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Hispanic Cancer Patients' Attitudes Toward Internet Cancer Support Groups

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Hispanic Cancer Patients' Attitudes Toward Internet Cancer Support Groups

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Dedication

To the Lord

To my family

To all of my friends

Acknowledgements

My lifelong dream of obtaining a graduate education, culminating with receiving a doctorate, has often been an escape from day-to-day life. The fantasy of gaining a graduate nursing education has turned to reality, and I have grown from this wonderful learning experience along the way. My hope is that many more individuals will also experience one of the greatest challenges in education, the doctorate.

My appreciation goes to my chair and co-chair, Drs. Eun-Ok Im and Sharon Brown. I was in the first class that Dr. Im taught at the University of Texas and grew fond of her research. She allowed me to participate in her research team and to make oral and poster presentations internationally, including in Korea and Canada and all over the United States on behalf of the research team. I thank you, Dr. Im, for believing in me, even when I did not believe in myself. She also allowed me to participate in writing several manuscripts accepted by top-tier journals, including *Nursing Research*, one of the most widely read nursing research journals.

Dr. Brown offered so much scholarly advice and greatly helped when one of my committee members was not able to continue on my dissertation committee. Dr. Brown's diligent efforts helped me to think past the framework of my biased Hispanic viewpoints. I know that there were times of frustration for both of us, but we both prevailed in the end!

To Drs. Carter, Chee, and Volker, I thank you for your diligent efforts in helping me with the numerous reviews of my study and for offering such scholarly advice and wisdom.

I would also like to thank all of my family members and my large group of friends in the community and at work. As I studied support groups, I realized that I was taking advantage of the best support system being made available to me—all of you! I owe so much to you all, and I thank you for always supporting me and never giving up on me.

Lastly, to my father, I thank you for showing such courage while experiencing the horrors of being diagnosed with cancer and then dying with dignity from this disease. How ironic that I always feared cancer, but during this study I interviewed 30 brave souls dealing with cancer struggles similar to my father's. I had the privilege of learning more about cancer and about people who were not afraid of the illness or of dying from it. I thank you all for the wonderful lessons I encountered during this journey.

Preface

As a second-generation Hispanic reared in a socioeconomically disadvantaged family in Central Texas, I have strong personal and familial experience with being disadvantaged in the United States, including in the health care system.

Hispanic influence pervaded my upbringing. My father was born and lived in Coahuila, Mexico, until he swam across the Rio Grande in an effort to start a new life. My mother was born and lived in Central Texas until she was 18 months old, when her mother died. She then grew up in Coahuila and eventually moved back to the United States.

After my parents married, they worked in the United States as migrant laborers; both were exposed to pesticides. Throughout my childhood, they told stories about such trials of working and living in the United States. Their first child was stillborn, and my father eventually died from cancer. I wondered, did these events have any correlation to their pesticide exposure?

As a child, I had asthma and received some type of treatment, but no one ever asked about our housing situation or any other factors that might have contributed to my medical condition. My entire family—parents and three children—lived in a one-bedroom, cockroach-infested efficiency.

In short, I relate very well to being uninsured and often not receiving basic health care, much less any in-depth preventive or diagnostic insights.

Fast-forward many years to when I started the doctoral program at the University of Texas at Austin. There I began to learn much more about underserved populations. My interest was further piqued when I discovered that many Hispanics today still experience situations like I did in my childhood. This knowledge heightened the awareness and interest in Hispanic issues that started in my childhood.

Hispanics with health care needs are often vulnerable and disadvantaged; yet, they have no voice to express their views about the inequalities they face. My position as a health care provider and the knowledge from my ongoing education give me a stronger voice than most disadvantaged Hispanics.

The aim of my academic pursuits, beyond broadening my capabilities as a health care provider, includes exploring my abilities to provide a voice for the disadvantaged, including Hispanics. This study, though only part of that journey, was important because it provided personal insight, as well as information that should help advance health care for Hispanics.

Personal insight started with following the recommendation of Rubin and Rubin (1995), who encouraged the use of like researchers interviewing like participants in a study. However, this process was a drawback in analyzing the results of the study. My intimate knowledge of socioeconomically disadvantaged Hispanics and their culture helped me interact with study participants, but I repeatedly faced strong temptations to impose personal viewpoints and interpretations, thus not fully allowing the data to stand on its merits.

The findings coalesced after an iterative process of analyzing the results and then rigorously checking to ensure that no intrusion of preconceived attitudes occurred in the interpretation of the results. At the end of the process, the weakness was turned into strength; awareness of personal bias prompted such thorough checking that the data were free of any preconceived interpretation. Ultimately, only the voices of the participants were heard.

However, the categorization and arrangement of participants' comments may still appear to have reflected bias because I inherently added beliefs and attitudes commonly held in Hispanic culture in the United States. These beliefs and attitudes so frequently arise in the culture that study participants and I assumed some statements were made in that context, even though participants might not have overtly stated them. For example, when I discussed participants wanting more online use of Spanish, I placed the topic under the theme of empowerment because it is a commonly held belief, and common sense, that using Spanish is respectful and empowering to Spanish speakers in almost all situations.

While a philosophically large theme such as empowerment is important, perhaps the largest impact of the study will come from its more basic facts, such as highlighting the barriers to Internet communication. Because such facts are tools, ready to be used by other researchers, support group designers, and others, these facts help satisfy my personal desire to help disadvantaged Hispanics and interpret their issues to puzzled outsiders.

Thus, all of these experiences in my doctoral journey have allowed me to further develop personally in terms of taking care of socially disadvantaged Hispanics and improving my quality of nursing care. Interpersonal relationships and communication skills were also further refined through this process.

Hispanic Cancer Patients' Attitudes Toward Internet Cancer Support Groups

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Previous studies suggest that the reasons that Hispanics do not use support groups might include utilizing the family as an informal support group structure, the use of spiritual support, language barriers, the lack of access to a computer and the Internet, the lack of face-to-face interactions in Internet groups, and the lack of cultural competence. Therefore, the purpose of this study was to explore the attitudes of Hispanics toward Internet cancer support groups (ICSGs) and reasons for the lack of participation in ICSGs.

In this feminist qualitative study, 30 Hispanic individuals who were receiving cancer care were contacted for telephone interviews. The participants were interviewed to obtain their responses to questions related to current use and interest in using ICSGs. The researcher used qualitative thematic analysis to analyze the data.

Four major themes arose. They were the need for a strong social network, attitudes about information access, concrete barriers to obtaining support, and the need for respect and empowerment. The major theme of “a strong social network” includes five sub-themes: (a) differences in online and face-to-face communication; (b) loneliness, isolation; (c) existence or lack of familial support; (d) spiritual support; and (e) informal support. Participants had mixed attitudes about information access. Positive attitudes were more common and included wanting to learn about their disease and learn how to obtain information and support via computer. Some participants did not want to obtain information, and some had negative attitudes about learning to use the computer. Many participants did not own a computer and had transportation problems that limited their access to a computer. The theme involving the need for respect and empowerment addressed the empowering use of Spanish in support of Hispanic cancer patients and empowerment via the group leader, who was Hispanic. The findings suggest a need to develop culturally competent ICSGs for Hispanics. One goal would be to augment instead of replace support. For example, an ICSG could have a spiritual basis, or there might be several ICSGs—one each for patients, families, and supporters such as friends from church. ICSGs also could target people without these supports. The existing knowledge should be used to provide direction for future research and for the development of cancer support groups that could meet the unique needs of Hispanic cancer patients.

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Chapter 1: Introduction

Cancer support groups have been shown to be beneficial in helping patients with coping strategies and psychological well-being (Cella, Sarafian, Snider, Yellen, & Winicour, 1993; Coriel & Behal, 1999; Presberg & Levenson, 1993; Samarel, Fawcett, & Tulman, 1997). Numerous individuals have taken advantage of the benefits from Internet cancer support groups (ICSGs) (Childress & Asamen, 1998; Crandall, Zitzelberger, Rosenberg, Winner, & Holaday, 2001; Curl & Robinson, 1994; Fawcett & Buhle, 1995; Fernandez et al., 2004; Forkner-Dunn, 2003; Im & Chee, 2005). However, members of the Hispanic participation in traditional face-to-face support groups seem to be lacking (Kaskutas, Weisner, & Caetano, 1997; Lieberman & Snowden, 1994; Guidry, Aday, Zhang, & Winn, 1997; Miano, Rojas, & Trujillo, 1996; Juarez, Ferrell, & Bornemen, 1998; Palos, 2004).

For this dissertation study, 30 Hispanic individuals who were receiving cancer care and follow-up at a cancer specialty clinic were contacted for telephone interviews. The participants were interviewed in order to obtain their responses to specific interview questions (listed in Chapter 3, Methods) related to current use of and interest in using ICSGs.

The uniqueness of this study is that it evaluated the specific cultural aspects of a small segment of the Hispanic population in the area of attitudes toward the ICSGs and possible reasons for a lack of participation in them. Several factors could explain why there is a lack of participation of Hispanic cancer

patients in ICSGs. Identification of these factors assists in understanding the lack of participation of the Hispanics in ICSGs.

Previous study findings suggest that the reasons Hispanics do not use support groups might include utilizing the family as an informal support group structure (Marin & Marin, 1991; Sabogal et al., 1987; Siantz, 1994; Ashing-Giwa, Padilla, Tejero, & Kim, 2004a), the family's attitudes toward cancer and health (Harmon, Castro, & Coe, 1996; Salazar, 1996; Solis, 2004; Harris, 1998), the use of spiritual support (Ashing-Giwa et al., 2004b; Culver, Arena, Antoni, & Carver, 2002; Juarez et al., 1998; Mickley & Soeken, 1993; Salazar, 1996; Siantz, 1994), language barriers (Ting-Toomey, 1999; David & Rhee, 1998; Ashing-Giwa et al., 2004b; Ellington, Sahami, & Mooney, 2003; Salazar, 1996; Solis, 2004; Uniken Venema, Garretsen, & Van Der Mass, 1995), gender roles (Salazar, 1996; Ellington et al., 2003; Lieberman & Snowden, 1994; Kessler, Mickelson, & Zhao, 1997; Meissen & Warren, 1994), the lack of access to a computer and the Internet (Levy, Price, & Tucker, 2002; Lazarus & Lipper, 2002; Fox & Rainie, 2000; Taylor, 2002; Kalichman, Benotsch, Weinhardt, Austin, & Luke, 2002; Latimer, 2001; Hoffman, Novak, & Schlosser, 2000), the lack of face-to-face interactions in Internet groups (Klemm, Hurst, Dearholt, & Trone, 1999; Samarel et al., 1998; Guidry et al., 1997; Weinberg, Schmale, Uken, & Wessel, 1996; Deason-Culver, Gerr, & Frumkin, 1997; Evans, 2001; Wright, 2000), and finally, the lack of cultural competence (Im, Guevara, & Chee, 2007).

While researchers have demonstrated that family often fulfills the need of a support group for the cancer patients, other researchers have revealed the

benefits of a structured support group system for the Hispanic population (Carpinello, 1995; Brown, Garcia, Kouzekanani, & Hanis, 2002). Yet very little is clearly known about Hispanic cancer patients' attitudes toward ICSGs. This study contributes to the development of nursing knowledge in this little-researched area of Hispanic cancer patients' attitudes toward ICSGs and provides an understanding of why there is a lack of participation of Hispanics in the groups. Very little research has been done with the Hispanic population regarding ICSGs. Therefore, the need exists to investigate further what the Hispanic attitudes are toward ICSGs.

PURPOSE

The purpose of this study is to explore the attitudes of Hispanics toward ICSGs and possible reasons for a lack of participation in ICSGs. For the study, data were collected on 30 Hispanic cancer patients. The long-term goal is to conduct further studies of Hispanic cancer patients' attitudes with a larger number of participants in order to further develop and meet the needs of potential participants on the Internet medium who might be interested in the Internet format in the future and, ultimately, to provide future directions for the development of ICSGs for Hispanic populations.

Research Questions

Research Question 1: What are the Hispanic cancer patients' attitudes toward Internet cancer support groups?

Research Question 2: What are the differences in attitudes toward ICSGs between participants who are interested and those who are not interested in participating in ICSGs?

SIGNIFICANCE OF THIS STUDY

Hispanics represent 13% of the total U.S. population, or 35 million people (U.S. Census Bureau, 2004). About 77.5% of the Hispanics are of Mexican origin, followed by Puerto Rican (9.7%), Central American (5.1%), South American (4.0%), Cuban (3.5%), Dominican (2.3%), Spanish (0.3%), and other descent (U.S. Census Bureau, 2004). This study does not make any delineation in types of Hispanics, although, given the geographic location, the vast majority of the targeted sample was Mexican American. This study uses the term *Hispanics* instead of reporting on each subset of the Hispanic population.

While Hispanics represent the largest racial and ethnic minority in the United States, they are still facing massive challenges that continue to affect their quality of life (Doty, 2003; Schur & Feldman, 2001). The most alarming area of concern is that of health (Health Coverage in Latino Communities, 2001). Hispanics are confronted with many health challenges including the incidence of chronic and infectious diseases and limited access to health care (Doty; Schur, & Feldman).

Cancer is the second-leading cause of death in the United States. Cancer accounts for 20% of deaths in Hispanics (American Cancer Society, 2009). The median age at diagnosis of cancer in Hispanics is 62 years. Overall, about 1 in 2 Hispanic men and 1 in 3 Hispanic women will be diagnosed with cancer in their

lifetimes. Furthermore, Hispanics' lifetime probability of dying from cancer is 1 in 5 in men and slightly more than 1 in 6 in women (ACS, 2009). The American Cancer Society (2009) estimates that 562,340 Americans will die of cancer in 2009 alone, which is more than 1,500 people a day. In the United States, cancer accounts for 1 of every 4 deaths.

The risks of cancer may differ based on a Hispanic subgroup's background, including whether they are U.S. or foreign born and their country of origin, heritage, degree of acculturation, or socioeconomic status. The U.S. population of Hispanic descent carries a cancer burden similar to that seen in the countries from which they emigrated. Compared to rates in the United States, the incidence rates of breast, colon and rectum, lung, and prostate cancers are lower in Puerto Rico, Cuba, and Central and South American countries than in the United States, but rates of cervical, liver, and stomach cancers are higher (American Cancer Society, 2006).

While rates of some types of cancer may be lower in Hispanics than in non-Hispanic whites, it should be noted that approximately 2 out of every 10 Hispanic families lived in poverty in 1990, compared with 1 out of every 10 non-Hispanic families. More Hispanic females, children, and elderly were living in poverty than non-Hispanics, and poverty rates vary among Hispanic groups (U.S. Census Bureau, 2004). Increased poverty levels in any group often occur concomitantly with the diagnosis of cancer and constitute a major barrier to accessing early diagnosis and ongoing treatment and support, including access to support groups through face-to-face means or via online support groups.

Guidry et al. (1997) researched the roles of formal and informal social support networks in overcoming barriers to treatment for Caucasian, African American, and Hispanic patients with cancer. The results showed the significance of support networks in assisting the cancer patients with continuing their treatment. An important finding indicated that health professionals did not provide information regarding support groups to the cancer patients at the time of the diagnosis. Fewer than half of the participants were asked whether they would be interested in joining a formal support group. The minorities were more apt to report that the support group networks helped with continuing treatment. Furthermore, the informal support group networks, such as the extended families, were seen as being more helpful for Hispanics as compared with whites.

A further possible explanation for a lack of support group participation of Hispanics might be related to the late-stage cancer diagnosis. Roetzheim et al. (1999) discovered that Hispanic patients lacking health insurance and persons insured by Medicaid were more likely to be diagnosed with late-stage cancer at diverse sites. The racial differences in the stage of diagnosis were not explained by insurance coverage or socioeconomic status. Efforts to improve access to cancer-screening services are warranted for these patients.

In addition to late diagnosis and treatment, additional economic barriers, such as a lack of finances and insurance coverage and challenges in communicating with the physicians, might explain why the support group resource is a lower priority for the Hispanic population. Guidry, Aday, Zhang, and Winn (1998) reported multiple economic barriers to cancer treatment including

lack of insurance coverage, costs of transportation and lodging, and costs associated with lost work days. Additional barriers included paying for insurance premiums, medications, diagnostic testing, and hospitalizations. The Hispanic population had noticeably higher out-of-pocket expenses for cancer treatments due to inadequate insurance coverage. Moreover, Ashing-Giwa et al. (2004a) showed that Hispanics faced difficulties accessing quality care, obtaining health insurance, and communicating with physicians due to language differences, physician time constraints, insufficient knowledge about the disease process, and a lack of control over the treatments. Thus, complementary and alternative therapies, such as dietary and herbal therapies, are used widely by patients (Lee, Lin, Wrensch, Adler, & Eisenberg, 2000; Alferi, Antoni, Ironson, Kilbourn, & Carver, 2001) as adjunct therapy to increase the potential benefit of standard cancer-related treatment. In general, Hispanic women who had a higher educational level or income, were younger, had private insurance, and exercised or attended support groups were more likely to use alternative therapies. Thus, the alternative and complementary modalities might have substituted for the support group structure for this population.

Juarez et al. (1998) concluded that Hispanic culture, family beliefs, and religion contributed significantly to the management and expression of the cancer pain. Patients approached pain stoically; they also demonstrated reliance on folk beliefs and non-drug interventions. It was useful to approach the patients by being nonjudgmental, sensitive, and above all, respectful of the individual. Once again,

the aspect of culture, family, religion, and folk beliefs probably sufficed as the support group structure needed for this group.

Support groups tend to build genuine interpersonal resources for the group members and their families (Gartner, 1982) by helping people learn from the experiences of others (Silverman, 1982). Nearly 10 million people in the U.S. take part in self-help, mutual aid, and support groups yearly (Lieberman & Snowden, 1994). Of these groups, 33%–50% are established for those suffering from chronic ailments such as cancer, heart and lung disease, arthritis, and diabetes (Wuthnow, 1994). Statistics reported by foundations for common chronic diseases have revealed that the groups and their programs help between 20% (Powell, 1990) and 66% of newly diagnosed patients in a given year (Checkoway, Chesler, & Blum, 1990). A study on support group participation by cancer patients during the first year after diagnosis showed a smaller figure may be more accurate because only 14.2% "received counseling or joined a support group" (Hewitt, Breen, & Devesa, 1999, p. 1482).

Davison, Pennebaker, and Dickerson (2000) evaluated patterns of patient support, both in face-to-face support groups and through the use of Internet support groups. The investigation of support-seeking behaviors indicated that people suffering from disorders that are both stigmatizing and serious (such as AIDS, alcoholism, breast cancer, or anorexia) are most likely to want help from face-to-face support groups. People are not as likely to seek support for equally serious but less stigmatizing illnesses such as hypertension, migraines, ulcers, and chronic pain. Similar patterns emerged with the online support groups as the

participants on the Internet support groups had the highest levels of support activity in areas of multiple sclerosis, chronic fatigue syndrome, breast cancer, and anorexia. The lowest activity areas were noted for participants who had chronic pain, ulcers, hypertension, and emphysema. The researchers posit that the online and face-to-face support patterns were significantly correlated, which suggests that broad tendencies to seek support vary by diagnostic category. However, as noted above, Caucasians and African Americans benefit from support groups (Cordova et al., 2003; Coriel & Behal, 1999; Henderson & Fogel, 2003; Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004), but very little is known about the Hispanic population and support groups, especially with ICSGs.

A significant need exists to learn more about Hispanics and ICSGs. As the previously cited studies show, Hispanics are a growing population with health challenges such as high cancer rates and often-limited access to health care, including social support services, which can be helpful for patients. Support groups, including ICSGs, can increase social support for Hispanics, just as support groups have helped other populations. Though only sparse data exist on Hispanics' use of support groups, minorities historically make inadequate use of support groups, even groups for people with cancer, which is in the category of stigmatizing diseases that often trigger patients to seek support groups.

This study's focus on ICSGs helps researchers and health care providers understand the unique possibilities of Internet support groups for Hispanics, and the ICSG information also provides insights on Hispanics' attitudes toward all

support groups. This knowledge should provide future directions for other research and for the development of cancer support groups that could meet the unique cultural needs of Hispanic cancer patients.

STATEMENT OF THE PROBLEM

Despite the growing Hispanic population in the United States and the large proportion of Hispanic cancer patients among ethnic-minority cancer populations, there is a paucity of information regarding the Hispanic cancer patients' attitudes toward ICSGs. In fact, few studies directly focus on support groups and Hispanics, and even less research exists on cancer support groups and Hispanics. Part of the problem is the difficulty of enrolling Hispanics in almost any research study due to lack of trust and access. However, a way to overcome the challenge of including Hispanics in any research study is to employ culturally competent recruitment strategies, such as Im et al. (2007) recommend, which were employed in this study.

In an effort to explain why support groups are important to the care of people with cancer, Bottomley (1997) reviewed studies of cancer support groups, which were led by professional groups. The researcher affirmed that many cancer patients receive very minimal formal psychological interventions. The study supports the use of support groups as a forum, which cancer patients might use to overcome the psychological trauma that often is associated with the cancer diagnosis, treatment, and relapse.

However, some information that relates to Hispanics is in published research about various kinds of support groups (Ashing-Giwa et al., 2004b;

Haynes & Smedley, 1999; Miller, Wilder, Stillman, & Becker, 1997; Ries et al., 1994; Shinawaga, 2000). Such research helps identify the multiple, multifaceted problems discouraging Hispanics from using ICSGs, as well as the positive points for Hispanic involvement (Carpinello, 1995; Ashing-Giwa et al., 2004b).

It has been suggested that Internet support groups, including ICSGs, can help patients but only if patients participate (Klemm et al., 2003; McTavish et al., 1995). Hispanic participation in support groups of all kinds is lacking for a variety of reasons, including utilizing the family and friends as an informal support group structure (Marin & Marin, 1991; Sabogal et al., 1987; Siantz, 1994; Ashing-Giwa et al., 2004a). Hispanics' many unfulfilled health needs and the paucity of Hispanics in research, including studies on all types of Hispanic support groups (Carpinello, 1995; Ashing-Giwa et al., 2004b), show the importance of studies such as this one exploring the attitudes of Hispanics toward ICSGs. Knowing about such attitudes would help researchers and health care providers better address the problem of Hispanic participation in support groups and other parts of the health care system. The significance of the problem to nursing practice includes a better understanding of how providers might know how to refer Hispanics to online support groups or to better understand the reasons that Hispanics are not yet using the Internet support group structure.

DEFINITIONS

The terminology used in this dissertation is defined as follows:

Attitude "is the predisposition of the individual to evaluate some symbol or object or aspect of his world in a favorable or unfavorable manner. Opinion is

the verbal expression of an attitude, but attitudes can also be expressed in non-verbal behavior. All attitudes include beliefs. When specific attitudes are organized into hierarchical structure, they comprise value systems" (Katz, 1960, p. 164).

Culture "refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values and/or institutions of racial, ethnic, religious, and/or social groups. Culture mediates between human beings and chaos, influences what people perceive, and guides their interactions" (Lipson & Dibble, 2005, p. xi)

Face-to-face support groups consist of people who share a problem and gather regularly to share their experiences in attempts to facilitate coping. Support groups consist of "clusters of like-minded or like-afflicted individuals who share experiences and offer one another mutual support and aid" (Butler, Gertman, Oberlander, & Schindler, 1979, p. 96). The term *support group* has its origins with groups associated with clinical services (Toseland, Rossiter, Peak, & Hill, 1990) and identifies people who are directed by professionals, whereas peer support groups, self-help groups, mutual aid groups, and mutual help groups suggest those that seem to be mostly member-directed (Ramsey, 1992).

Hispanic is from the Latin word for *Spain* and has a broad reference, potentially encompassing all Spanish-speaking peoples and emphasizing the common denominator of language among communities that sometimes have little else in common (Webster's Online Dictionary). The federal government defines a Hispanic as a person of Mexican, Puerto Rican, Cuban, South or Central

American, or other Spanish culture or origin regardless or race (U.S. Census Bureau, 2004). For this dissertation, the term *Hispanic* is used for all subsets of the Hispanic population.

The *Internet* is the system of interconnected computer networks that carries various forms of information and services, such as electronic mail (e-mail), online chat, and interlinked web pages (Thurlow & McKay, 2003).

Internet support groups consist of people who communicate by using the Internet about a shared problem. Some of these groups are moderated by professionals. However, the majority of Internet support groups have leadership by lay people with a personal interest in the shared problem (Im, Chee, Tsai, Lin, & Cheng, 2005).

Internet-based communication refers to communication between people that occurs through the Internet via a computer. Examples of this are e-mail, websites, chat rooms, and instant messaging (Beard & Wolf, 2001).

Online refers to anything that is based in the Internet, and *offline* refers to anything that is not Internet related (Suler, 1996).

"*Social support* is defined as the exchange of resources between at least two individuals, the provider and the recipient, with the intention of improving the well-being of the recipient" (Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002, p. 846).

ASSUMPTIONS

The study is based on the following underlying assumptions:

- The diagnosis of cancer and its treatment is intrinsically stressful for the patient, family members, and friends.
- Cancer support groups are important sources of social support for some cancer patients.
- An ICSG is a type of cancer support group that is also a great source of social support for some cancer patients.
- Individuals are capable of describing their attitudes regarding ICSGs.
- ICSGs may or may not be useful for Hispanics with cancer.

LIMITATIONS

A limitation of this study would be that the participants in the study tend to be a limited group of Hispanic cancer patients and not representative of the Hispanic population in general. The sample in this study is primarily from one cancer care clinic, and thus the participants might have attitudes that are perhaps different from those of Hispanics who were not involved in this telephone interview study.

Another limitation of this study involves the lack of representation among the diverse subgroups of Hispanics in the United States. Conversely, the Hispanics are referred to as a single ethnic group. According to the U.S. Census of 2004, 60% of Hispanics in the United States were of Mexican descent, and 10% were of Puerto Rican descent. About 4% were of Cuban descent, and the rest were of other Hispanic descent (U.S. Census Bureau, 2004). In this study, the sample of participants mirrors the national percentage of about 73.3% of Mexican

descent (U.S. Census Bureau, 2004) and 24.3% in Texas (Texas State Data Center and Office of the State Demographer, 2000).

The telephone interview method of data collection presents some challenges in using this particular method for data collection for the researcher. The disadvantages of using the telephone interview method include the following: 1) this method is often difficult when one does not have an established partnership (Rubin & Rubin, 1995), 2) the researcher does not meet the person face to face; therefore, conversational cues are lacking, making this a challenge (Rubin & Rubin), 3) there is a lack of contextual naturalness (Holstein & Gubrium, 2005), 4) the difficulty of maintaining participant involvement is related to a lower rate of cooperation (Musselwhite et al., 2007), 5) maintaining clear communication is challenging due to the participants' being indecisive (Musselwhite et al.), and 6) communicating with a third party instead of the participant presents another level of challenge (Musselwhite et al.). Researchers sometimes have difficulty in making contact with the participant due to another family member requesting to provide the information to the researcher (Musselwhite et al.). Thus, there are challenges in using this type of methodology for data collection with the Hispanic population in this study. In particular, the researcher was not able to communicate with those participants who do not have a telephone, and the researcher was not able to observe the settings and contexts where the interviewees live.

In helping to overcome the potential challenges of using the telephone interview method, several strategies were employed. First, a relationship was initiated with the participants at the cancer clinic. It is at this crucial time that the

researcher began making initial face-to-face contact with each participant. Oftentimes, the patients were at the clinic receiving chemotherapy; thus, the researcher had an extended period of time to visit with the potential participants about the purposes of the study and had an opportunity to begin to develop a relationship with the individual that was useful in establishing rapport for the upcoming telephone interviews. In addition, the incentive of a modest gift card helped to keep participants involved. It is also at this initial contact time that both the researcher and the participant met for a preliminary explanation of the study. An emphasis was made that it would be important to make direct contact with the participant instead of any family members, who might desire to be interviewed for the study. Finally, the researcher went to the outpatient clinic one additional time in order to follow up with those participants who did not follow up with the phone interview. Importantly, keeping to one follow-up visit ensured that there was no coercion for the individuals to participate in the study.

SUMMARY

This study is an exploration of Hispanic cancer patients' attitudes toward Internet support groups through an evaluation of qualitative data. Existing research provides few insights about Hispanic cancer patients' culture-specific attitudes toward ICSGs (Kaskutas, Weisner, & Caetano, 1997). An understanding of Hispanic cancer patients' attitudes toward ICSGs is essential if providers are to encourage the Hispanic population to participate in Internet support groups. In this chapter, the purpose of the study was described with specific research

questions, the study's significance, statement of the problem, definitions of terms, and underlying assumptions. Finally, limitations of the study are discussed.

Chapter 2: Theoretical Background and Literature Review

In this chapter, the theoretical background of this study is described and a review of the literature related to Internet cancer support groups (ICSGs) is provided. First, the common theoretical background of this study is discussed, which includes feminism in general, diverse feminist thoughts, and the feminist approach taken. Second, a critical analysis of the literature relevant to this study is included, which is an analysis of Hispanic cancer patients' attitudes toward Internet support groups. The critical review of the literature includes literature on native-born patients and Hispanic immigrants in the United States, an overview of Hispanic culture, Hispanics' cancer experience, and ICSGs. Another section includes the challenges in studying Hispanics' views of ICSGs. Third, a theoretical framework that incorporates a socialist feminist perspective is included, based on a review of the literature, which guided this study's research. Finally, a summary is provided.

THEORETICAL BACKGROUND OF THIS STUDY

Cancer support groups have proven to be effective and beneficial in helping patients deal with the initial shock of a cancer diagnosis as well as in offering treatment options and emotional support (Cella et al., 1993; Coriel & Behal, 1999; Presberg & Levenson, 1993; Samarel, Fawcett, & Tulman, 1997). Indeed, cancer support groups positively affect quality of life, lessen mood disturbances, improve coping responses, and prolong life (Spiegel, 1995). Other studies have reported the uniqueness of the group setting for promoting

therapeutic outcomes, which are not obtained in individual psychotherapy. For example, the feeling of belonging to a group, receiving understanding, and gaining acceptance may increase feelings of self-worth and help to decrease alienation (Cella & Yellen, 1993; Yalom, 1985).

Research conducted on cancer support groups has suggested the importance of including the research participant's point of view pertaining to involvement in a cancer support group. Science involves a myriad of procedures and conclusions, many of which are apt to miss the significance of the participants' personal experiences (Harding, 1987). When science is applied to foster a majority of androcentric and ethnocentric opinions and concerns, the individuals not belonging to this dominant group seem insignificant, and their needs are either ignored or inaccurately displayed in research (Campbell & Bunting, 1991; DeMarco, Campbell, & Wuest, 1993; Ford-Gilboe & Campbell, 1996; Im & Chee, 2003).

For a different perspective that respects and highly values the opinions of study participants, the feminist perspective provides a useful framework for research (Hall & Stevens, 1991; Thompson, 1991). Feminists hold that pure biology does not relate to everyone because people exist in assorted environments (Allan, 1993; MacPherson, 1983; Young, 1990). Instead, feminist ideology places gender as a dominant characteristic that involves other factors, such as ethnicity or social status, to build relationships between individuals (Rosser, 1994). Meleis (1997) referred to this theory as being *gender-sensitive*.

In this study, a feminist stance framed the research process. Thus, Hispanics' attitudes concerning cancer support groups were viewed to come from their unlimited communications with their settings and from biases showing how they and their health care providers see the world (Young, 1990). Also, in this study, a theoretical framework that was developed based on a systematic literature review was used to theoretically guide the study. The framework is explained at the end of the chapter. The next section discusses the feminist view on ICSGs, diverse feminist thoughts, and the socialist feminist perspective this study used.

Feminism

The feminist viewpoint appreciates the indivisible integrality of people and their environments (their sociocultural systems, including health care) (Chinn & Wheeler, 1985; Comas-Diaz, 1991; MacPherson, 1983; Offen, 1988). Chinn (1992) said feminism includes focusing "on creating self-love and respect for all others and for all forms of life" (p. 128). Feminist theories describe the oppression of women and powerless groups and propose ways to eliminate oppression (MacPherson) through emancipation (Allen, Allman, & Powers, 1991; Gortner, 1997) and from patriarchal societies' social directives (Anderson, 1991; Chinn & Wheeler, 1985; Crotty, 1998). Feminist research encourages the enhancement of women's lives (including their health), building helpful relationships between the researcher and the participant, and enabling women to recognize the causes of their afflictions (Anderson; Stevens, 1993). There has been an oppression of Hispanics and this group is often very powerless in terms of poverty and social status. Thus, Hispanics' lives may be enhanced by a researcher treating the

participants with respect and by placing value and significance on the exchanged communication (Fawcett & Buhle, 1995). All these characteristics of feminism have potential applicability to the study of Hispanics and their attitudes toward ICSGs. One of the goals of feminist research is to establish an open relationship between the researcher and the participant (Stevens, 1993); therefore, it was helpful in this study to interact with the Hispanic participant and collect the data by using a feminist framework of study.

Diverse Feminist Theories

An Overview of Philosophical Approaches to Feminist Theory

Feminist theories provide insight into women's repression and offer solutions by promoting new ideas of justice and freedom for women (Liaschenko, 1993; MacPherson, 1983). Five primary philosophic approaches to feminist theory are (a) liberal, (b) traditional Marxist, (c) social, (d) cultural, and (e) radical feminism (Chinn & Wheeler, 1985; MacPherson).

Liberal feminist theory focuses on equality of opportunity for women and the unequal distribution of wealth, position, and power based on family, race, and sex (Chinn & Wheeler, 1985). The root of injustice to women is found in unequal civil rights and educational opportunities. The liberal feminist perceives that oppression can be eliminated by targeting gender partiality and by offering legal rights and opportunity for women (Bunting & Campbell, 1990).

Traditional Marxist feminist theory distinguished the source of women's oppression historically in the institution of private ownership of property (MacPherson, 1983). According to MacPherson (1983), the origin of traditional

Marxist feminist theory is with women's oppression and private property. A class system of a relatively small number of men had private ownership of land and production in industrial societies. Support for this theory is generated by contemporary corporate capitalism and imperialism. Women and children, as well as material goods and the means of production, were the property of men. To free women from this control, a socialist revolution must occur, whereby the means of wealth and private property become the possession of society as a whole (MacPherson).

According to the socialist feminist theory, cultural customs, such as the patriarchal family, motherhood, housework, and consumerism, have a major impact on the injustice to women (Chinn & Wheeler, 1985). Socialist feminism emphasizes the central connection between the private domain of the family, personal life, and the public arena of productive work. The oppression of women and socioeconomic class oppression are seen as essentially important and mutually reinforcing. Notably, these cultural institutions are viewed as functioning distinctly within diverse classes such as the women's working class. Therefore, socialist feminists refuse the intimation made by previous feminists that most women are oppressed in similar ways. According to this view, elimination of the double oppression of a class-focused society and institutionalized gender discrimination is needed to free women from oppression (MacPherson, 1983).

Cultural feminists ascribe to the tenet of a basic difference between the genders. Notable inherent differences are in the areas of values, judgments, and

modes of thinking (Bunting & Campbell, 1990). Cultural feminists deem that women's oppression stems from the depreciation of feminine traits and overvaluation of masculine qualities such that there are cultural differences between the genders (MacPherson, 1983). Therefore, cultural feminists attempt to construct a social re-evaluation of feminine traits seen as women's strengths.

Radical feminist theory draws not from established social theories but from a woman-centered worldview. According to radical feminist theory, the oppression of women is fundamental, existing within all types of economic framework, and cannot be removed simply by altering the systems (Chinn & Wheeler, 1985). Radical feminists challenge the present opinions and language of patriarchal systems and strive to create ideologies stemming from a woman-identified viewpoint (White, 1991). A distinguishing characteristic of radical feminist theory is its starting point. Radical feminist theory stresses the idea of discovering, analyzing, and validating women's experiences without the standard of male perspectives or systems (Chinn & Wheeler, 1985). This theory focuses on the importance of implementing psychosocial changes and woman-defined systems of thought and culture.

This dissertation uses a socialist feminist view because Hispanics as a group are oppressed by the cultural norms of society (Chinn & Wheeler, 1985). Also, as a socioeconomic group, Hispanics often face discrimination in many areas of society (Flores & Mata, 1995). In Hispanic culture, the viewpoint and opinion of the Hispanic woman is oftentimes overpowered by the dominant Hispanic male perspective (Flores & Mata, 1995).

General, Socialist Feminist, Research Approach in This Study

Researchers should be cautious of androcentric and ethnocentric biases in a research study (Ford-Gilboe & Campbell, 1996; Porter & Villarruel, 1993). However, in all philosophic feminist perspectives**,** a feminist researcher must do much more. For instance, the feminist researcher is expected to employ his or her own unique identity in the interaction with the study participant throughout the interview process (Oakley, 1981; Tilden & Tilden, 1985). Feminist research tends to forsake the model of interviewing in which the interviewer receives but does not give information, the interviewer objectifies the interviewee as part of the data, and the interaction during the interview is devoid of personal meaning (Oakley)**.** A feminist researcher involves the participants in an open dialogue concerning their lives and experiences (DeMarco et al., 1993). Since feminist research allows the researcher and participant to know one another better, both parties can benefit mutually from their interactions (Anderson, 1991; MacPherson, 1983). The researcher and a participant collaborate and come to know one another at a deeper level, with the researcher viewing interactions from the participant's view and prioritizing all participants' views and experiences (Hall & Stevens, 1991)**.** During the interview, the researcher frequently shares potentially useful information with the participant (Anderson, 1991; MacPherson, 1983; McBride, 1984; Oakley)**.**

Ultimately, feminist research is more apt to be qualitative rather than quantitative in nature. Common methods are ethnography, grounded theory, and phenomenology (MacPherson, 1983). However, some researchers have argued

that a richer and more complete research study is accomplished by using techniques of triangulation that integrate quantitative and qualitative methods (Duffy, 1987; Im, Lee, & Park, 2002). In this study, the qualitative methodology offers a much more rich representation of the patient's responses to structured questions, thus providing meaningful data for an evaluation to study this particular phenomenon of Hispanic cancer patients' attitudes.

In reference to Hispanics, the researcher should employ culturally sensitive methods and flexibility in study designs (Meleis, 1996; Rehm, 2003). Since the Hispanic culture has strong hierarchical social systems and deference to various professionals (Falicov, 1982), both of which can encourage marginalization of some Hispanics, the feminist principle of using culturally sensitive methods and flexibility in designing research helps give all group members—both men and women—a more equal voice in the research. The upcoming section on Hispanic culture has more information on hierarchy, deference, and other Hispanic cultural values the researcher should keep in mind.

This dissertation study uses the feminist research principles delineated above, as applicable to the analysis, that is, interaction with subjects and an emphasis on qualitative data is achievable. In addition, the study focuses on many cultural factors influencing not only research but also Hispanics' attitudes toward ICSGs.

A REVIEW OF THE LITERATURE

To facilitate the discussion of the multifactorial elements affecting Hispanics' use of ICSGs, this section includes the discussion of published studies

into five categories, each of which involves specific variables that might affect conclusions about Hispanics' participation in ICSGs. The categories are (1) non-Internet support groups not specific to Hispanics, (2) Internet support groups in general not specific to Hispanics, (3) ICSGs not specifically focused on Hispanics, (4) Hispanic-specific studies, and (5) the difficulty in enrolling Hispanics in nursing research. At the end of each category, a paragraph is used to summarize the findings. The categories also help illustrate the paucity of Hispanic-specific data, thus the need for this study on Hispanics and ICSGs.

Non-Internet Support-Group Studies Not Specific to Hispanics

Numerous studies show, in a variety of ways, that minorities, including Hispanics, are underrepresented in support groups; sometimes the studies identify contextual influences on participation.

Among the non-Internet support-group studies not specific to Hispanics, the lack of non-whites in such groups is once again apparent because Taylor, Falke, Shoptaw, and Lichtman (1986) reported that cancer support group attendees are more likely to be white middle-class females, to report having more problems than non-attendees, and to use social support resources of all kinds more than non-attendees. However, a limitation to the study was that the sample was disproportionately female, white, and middle class to upper-middle class. Thus, the support needs of minority, working-class, and male patients were under-represented. Taylor also affirms that the support groups may be a redundant resource and appeal to the same segment of society that traditional mental health services appeal to, specifically, middle-class women. Lastly, the researchers

imply that a segment of the population might not be having their needs met with respect to cancer and other disorders. In particular, male, low socioeconomic status, and minority individuals are under-represented in cancer support groups and in other mental health services.

Cella and Yellen (1993), in a literature review of cancer support groups, affirmed the need for support groups that help to serve a large number of people with cancer and the family members. The researchers noted an under-representation of people of color, men, and the poor among group participants. The researchers concluded with the need for more resourceful and variable outreach methods to help underserved groups (a category that includes Hispanics because most studies show they are medically underserved and underrepresented in support groups). Coriel and Behal (1999) concurred with the need for outreach efforts to increase support group participation among underrepresented segments of at-risk populations, specifically the ethnic minorities of lower socioeconomic status.

Showing the potentially beneficial role of support groups, Cordova (2003) studied mood disturbance in community cancer-support groups. His aim included magnifying the roles of emotional suppression and the fighting spirit. His main finding was that the expression of a negative effect and an attitude of realistic optimism may enhance the adjustment and reduce the stress for the cancer patients in support groups. Such findings are among many documented benefits of support groups. If Hispanics and other minorities can overcome contextual and

other barriers to participation, they hypothetically should be able to enjoy such benefits of support groups.

Studies have shown cancer patients view cancer support groups positively. Such studies have primarily focused on support group structures, which have been traditionally conducted as hospital-based support groups. These hospital-based groups are less accessible to the Hispanic population (Camosy, 1996) because the Hispanic population is sometimes not being referred to this valuable network system.

People of minority backgrounds say social support networks assist them with continuation of cancer treatment (Guidry et al., 1997). Since support groups may be considered a type of social support network and the development of a supportive network is one of the benefits of a support group, health care professionals should be aware of the benefits of developing ways to reach out to minorities in order to increase participation in formal support groups. In Hispanics' definition of social support networks, they include extended family and friends (minorities use these two groups more than whites do). Minorities' receptivity to their definition of social support networks implies potential openness to support groups such as ICSGs, or perhaps minorities would use family and friends instead of support groups. Such unanswered questions show the need for a study on Hispanics and ICSGs.

This discussion of non-Internet support groups that were not specific to Hispanics showed minorities' low participation in support groups and other aspects of the health care system may contribute to their heightened health

problems and their troubles handling health problems. Though support groups have benefits for participants, several contextual factors may negatively influence minorities' participation. However, minorities say social support networks (one of the major benefits of support groups) help them. This potentially positive predisposition toward support groups (a type of social support network) may be negated by the fact that minorities use family and friends as major social support networks.

Internet Support Groups Not Specific to Hispanics

The literature on Internet support groups non-specific for Hispanics also provides indirect insight on Hispanics. For instance, Im et al. (2005) evaluated Internet support groups from a feminist perspective. The recent studies have indicated that the ICSGs tend to serve a highly educated, high income, white, male group, and members tend to be at an early stage of cancer. The researchers suggested that other researchers adopt multiple recruitment strategies, including quota sampling, which could assist to ensure the inclusion of subject types that are likely to be underrepresented in the convenience sample, such as women, minority groups, the aged, the poor, the rich and the undereducated, thus reducing potential selection bias.

Wright (2000) examined perceptions of support providers, social support network size and network satisfaction of online support providers. Of significance for this study is the evaluation of the advantages and disadvantages of computer-mediated support groups among 107 online support group users. One of the main advantages of using the online support group function was that this type of

interaction resulted in a lack of stigmatization that the participants felt from others when communicating within the group. A disadvantage mentioned by Wright pertained to the amount of "flaming," or negative comments that can occur during online communication, followed by deception by other members and slower feedback than in face-to-face interactions.

Mendelson (2003) evaluated Internet listservs as sources of support for women with lupus erythematosus. This disease typically affects women, and these women are oftentimes in need of much support in order to manage the daily symptoms associated with this disease process. For many women, the Internet fills the need for this type of support. The sample consisted of 90 participants, and the number of postings to the listserv included 1187 postings. Mendelson asserts that the flexibility of asynchronous listservs allowed the participants to check in at times convenient for the participants. Also, the ability of online communities to reach enormous geographic areas increased the potential to successfully maintain the listservs, which met the needs of the participants with the disease process. Lastly, Mendelson affirms that the virtual communities can provide an important source of support to persons with chronic illness.

Houston, Cooper, and Ford (2002) described the characteristics of users of Internet-based depression support groups and evaluated whether the use predicts change in depression symptoms and social support. The sample size included 103 participants, and the group was followed prospectively. The results indicated that over 50% of the participants greatly used the support group for five or more hours in two weeks. Additionally, 37.9% had a preference for using the online

communication system as opposed to the face-to-face counseling. Interestingly, the Internet depression support group users were mostly women with a median age of 40 years. The more-frequent users of the Internet groups were more likely to have a resolution of the depression symptoms during the follow-up as opposed to the less frequent users.

Kouri, Turunen, Tossavainen, and Saarikoski (2006) evaluated online discussions between families by using an Internet-based service designed for public maternity care in Finland. The study included 21 participants, and the data included experiences of family life during pregnancy, childbirth, and parenting. The researchers point out that the greatest obstacles in the use of the Internet are the potential threats to privacy and the participant's inability to assess the quality of the information and services available online. The participants in this study consisted of Finnish expectant families who were moderately computer literate. The main limitation of the study was that it did not involve foreigners. The advantages of the study were that the family members were able to stay at home or work and able to participate 24 hours per day. The authors concluded with the need to further examine whether virtual communities can substitute or balance face-to-face support groups.

Moloney, Dietrich, Strickland, and Myerburg (2003) evaluated methodological challenges and explored some of the issues related to using online discussion boards as virtual focus groups in a study of perimenopausal women with migraines. The researchers evaluated advantages and disadvantages of using the online system for the discussion board. The main disadvantages encountered

included maximizing the participation of all the group members in the discussion, minimizing the occurrence of misunderstandings, and controlling the direction of the group's conversation. Some of the group members were slow to participate in the discussion and required some promptings from the other members in order to participate. Another observation from the interactions was that some participants might be more open in an actual face-to-face setting as opposed to a virtual community setting. Still others might have a problem with distrusting the computer security and not be able to express themselves in a public manner. Yet others who might not own a computer, have very little experience with using computers, or do not have sufficient skills in typing might find the computer system to be challenging. The Internet system does not allow for nonverbal expressions such as facial changes, gestures, and tone of voice for communication purposes.

The researchers also discussed the noteworthy advantages of using the online discussion boards. Such advantages include an enhanced participant ease of using the computer system, potential for better quality of data obtained because of participant comfort, and potential time and cost savings for the researcher. Another advantage is that the Internet format provides a safe forum since the participants are not required to answer every question.

Internet support groups have been found to be especially helpful for individuals who are homebound and not able to physically leave the home (Martin & Youngren, 2000). The authors finally explain that ICSGs are able to meet the psychological needs of the patient and family. By using the support groups, the

patients are helped with feelings of isolation, powerlessness, alienation, anxiety, and misinformation. The authors also reveal that research has supported the finding that individuals at any age, with no previous computer experience, can learn to use computer networks successfully.

Bacon, Condon, and Fernsler (2000) described the Internet self-help phenomenon among a group created for use by widows with dependent children. The reasons they cited as being advantageous to the Internet support group option included widows who had challenges in traveling due to physical problems, a lack of transportation, expense and availability of child care, face-to-face meeting times that were not practical, living in remote areas, personal illness, sick children, and busy lifestyles. An advantage of using the Internet included using an already-available computer at the home. A descriptive survey was used to describe an electronic self-help group composed of widows with dependent children. The sample consisted of 24 women, and 90% of the women were white, 10% black, and 90.5% with some college education. The results of the study revealed that 85.7% ranked "having contact with others having similar experiences" (p. 28) as the most important reason. The second reason was that they desired emotional support from people who could be empathic. Communicating with others having similar experiences was considered the greatest motivating factor for participation in the group. Advantages to being on the Internet included feeling less intimidated, more open, and more at ease with strangers on the Internet and finding it easier to communicate by e-mail. Conversely, reasons for not participating included time constraints, experiencing

technical problems with the computer, a lack of technical skills, strong offensive language, a lack of privacy, a lack of physical touch, and misunderstanding of messages.

Taylor and Luce (2003) asserted that Internet-based psychotherapy programs have a great potential to make assessments and treatment more cost effective by reducing the time with the therapist. Additionally, the researchers affirm that computer-assisted therapy appears to be equally effective as face-to-face treatment for treating anxiety disorders and depression. Internet support groups may be effective and potentially have certain advantages over face-to-face therapy. Ultimately, there has been a scant amount of research on this topic. Indeed, few studies evaluating the effectiveness of computer-assisted instruction for giving information related to mental health or psychotherapy have been conducted.

Advantages of using an Internet support group as cited by Taylor and Luce includes the fact that Internet support groups may be accessed from any location that has Internet access and that the Internet groups offer advantages over face-to-face counterparts. Another advantage is that the Internet support groups have the potential to assist rural patients and people who are chronically ill or physically or psychiatrically disabled. Member communication is oftentimes equal to that found in face-to-face support groups.

Studies on Internet support groups suggest the importance of such support group structures in aiding social support for ethnic groups (Fernsler &

Manchester, 1997; Gustafson, Wise, McTavish, & Taylor, 1993; Klemm, Reppert, & Visich, 1998).

Internet Cancer-Support Groups Not Specific to Hispanics

As for online cancer-support groups, some studies provide direct or indirect insights about Hispanics. For instance, Klemm, Reppert, et al. (2003) analyzed a review of the research literature on online cancer-support groups. The researchers found that in 9 of the 10 published studies, online cancer-support groups helped people cope more effectively with their cancer. In other findings, 6 of the 10 studies did not include men, and six focused on Caucasian women with breast cancer. Only one of the studies (McTavish et al., 1995) had a minority population, which included eight African American women with breast cancer, who were of low socioeconomic status and educational level. Interestingly, higher depression rates and social isolation were associated with increased Internet use. The researchers affirm that the use of technology, which is necessary to access the Internet, is a comparatively new phenomenon and could possibly be a barrier to participation. Other barriers mentioned by the authors were low literacy levels and visual impairments. They further revealed that traditional face-to-face cancer support groups have under-representation among minority groups, men, elderly people, and people of low socioeconomic status. Participants more likely were younger and more educated, and this same disparity in membership seems to be true of online support groups as well. Thus, the research studies mainly focused on small groups of Caucasian women with breast cancer. Therefore, the results could not be generalized to a larger population of individuals with cancer. Further,

for online support groups, most are hosted in the United States, with English being the language of choice. Klemm et al. (1999) also recommended that attention should be given to facilitating the entry of underserved groups into the ICSGs. Thus, having the Internet as a support group structure does not change the under-representation of minorities in the support groups.

Im et al. (2005) noted that in doing Internet cancer research among ICSGs, minority patients definitely had limited access, with only a small number of ICSGs for any minority group. The researchers' final conclusion was that there are many problems involved in getting an adequate representation of all groups, verifying participants for inclusion, and addressing ethical and privacy concerns. Potential problems for the ICSG members included a lack of face-to-face contact, having to deal with the negative emotions expressed by others, and problems in assessing and verifying the posted information.

Nolan et al. (2006) described spiritual issues addressed by users of a pancreatic cancer informational web site. Six hundred postings on the cancer Web site were evaluated and the themes discovered were spiritual convergence, reframing suffering, hope, and acceptance of the power of God and eternal life. Importantly, 6% of the postings were by family members who were reporting on the death of the loved one. This finding suggested that the web site also served as a bereavement function for the family members. An implication from the study was that a separate chat room for bereavement was set up as a result of this study.

Owen, Yarbrough, Vaga, and Tucker (2003) examined communications among 167 males and females participating in ICSGs. The aim of the study was to

examine emotional disclosure and cognitive processing in online support groups by using a controlled, experimental design. It was hypothesized that females would show more emotional disclosure than males and that preparation directed toward increasing emotional disclosure would affect the communication of both males and females. Those eligible for the study included students who had access to the Internet and had a close friend or family member who had been diagnosed with cancer. A portion of the sample included 16.9% participants who were self identified as being Hispanic, Asian, Native-American or Arab. The sample was 28.4% male and 71.6% female. Surprisingly, gender differences in the content of the communication were not observed, and preparation for participation in the online group was not associated with greater emotional disclosure or cognitive processing in the expected directions.

Klemm, Hurst, Dearholt, and Trone (1999) evaluated gender differences on ICSGs. The aim of the study was to determine if categories of responses on ICSGs differed when the majority of the participants were of a single gender. A second aim of the study was to determine if the response categories observed on gender specific support groups were different than those used equally between men and women. Data were evaluated from prostate, breast and mixed ICSGs. The themes that emerged were information seeking and giving, encouragement and support, personal opinion, and personal experience. For the prostate male gender specific group, information seeking was rated as being first. Conversely, for the female breast cancer gender-specific group, personal experience was at the

top of this list. Interestingly, men were more twice as likely to give information, while women were twice as likely to give encouragement and support.

The researchers also stressed that the availability of Internet access has greatly increased and that very soon universal access to the Internet might be likely due the discovery of Web television. Another observation by the research team was the there was a lack of participation from underserved populations, an area that exists in traditional face-to-face support groups. An implication of this study is for nurses to support underserved populations in having access to information on the Internet. Finally, the Internet support groups might provide a creative medium for persons with rare cancers to seek information and support.

Klemm and Hardie (2002) examined depression in ICSGs as compared to face-to-face cancer support groups. An exploration between Internet use and levels of depression were evaluated in an exploratory descriptive design. A convenience method of recruitment for the 14 participants of the traditional face-to-face group and 26 from the ICSG were evaluated. All of the 14 participants in the face-to-face group were males. In the Internet group, 56% were male and 44% were female. There was no mention of ethnicity for either group. According to the researchers, the data suggested that the more depressed patients with cancer used the Internet support groups instead of the face-to-face groups. An implication from this study was that the efficacy of the ICSGs providing psychoeducation and psychotherapeutic intervention needs to be further studied.

Klemm, Reppert, and Visich (1998) refer to the ICSGs as nontraditional support groups. The researchers assert that the Internet support groups are a

means of recommending support to cancer patients, the families, and the caretakers in a very nontraditional arrangement. The important advantages of using the Internet support groups include 24-hour availability, accessibility for the homebound, a representation of diverse geographic locations, anonymity was stressed, and a potential for having more males to participate in the support group function. The disadvantages of the Internet support groups were cost of the Internet access, a lack of a professional facilitator for the group, the information posted might not have been reliable, individuals with low literacy levels might be excluded from participation, and visually impaired individuals might not be able to participate.

The preceding studies showed minorities could benefit from support groups, but few participate. Having support groups on the Internet did not change this pattern, partially because few minority-specific Internet groups exist and because whites use the Internet in general more than Hispanics do, so whites are more likely to access Internet support groups.

HISPANIC-SPECIFIC STUDIES OF INTERNET USAGE

Hacker and Steiner (2002) reported that Anglo Americans are more likely than Hispanic Americans to use the Internet and that they use it more frequently once they start using it. The data also showed that Anglo Americans are more likely than Hispanic Americans to achieve interpersonal communication benefits from using the Internet. Thus, according to these researchers, a digital divide does exist between these two groups.

However, Internet usage among Hispanics is growing. Similar to the general population's Internet usage (McCool, 2000), Internet usage among U.S. Hispanics reached the 50% mark in the fourth quarter of 2001 (HispanicBusiness.com, 2002; Van Camp, 2004; Wentz, 2004). Among Hispanic adults, 11 million had Internet access, and there was a 25% increase in that population in the 12 months preceding February 2001. By comparison, 58% of white adults had been online, and 43% of African Americans had been online (Pew Research Center, 2000). More of the Hispanic newcomers were women than men. Two thirds of the growth in Hispanic usage came from those under age 34; overall, 61% of Hispanic Internet users were 34 and under (Pew Research Center).

HISPANIC-SPECIFIC STUDIES OF CANCER EXPERIENCE AND SUPPORT GROUPS

There are Hispanic-specific data about some aspects of cancer and support groups. Researchers found that ethnic disparities exist for Hispanics and other minorities concerning cancer stage, diagnosis, and survival (Ashing-Giwa et al., 2004b; Haynes & Smedley, 1999; Miller et al., 1997; Ries et al., 1994; Shinawaga, 2000). For instance, Ashing-Giwa et al. (2004b) found that, because the diagnosis of cancer is often made when the disease is at an advanced stage in Hispanics, there are greater severity for morbidity and mortality. Also, when a late diagnosis occurs, there is often not enough time to become involved in either formal face-to-face or Internet support group structures. The upcoming discussion of research by Ashing-Giwa et al. and by Harmon, Castro, and Coe (1996) gives some clues why disparities such as these exist.

In their multiethnic study, Ashing-Giwa et al. (2004b) found that Hispanic women had less knowledge about their bodies and lacked awareness about the benefits of breast-cancer screening and early detection. Hispanic women had cultural taboos about touching their bodies, which often resulted in avoidance of self-exams and screenings. After some participants had a mastectomy, their husbands abandoned them. It was also noted that the women relied more on alternative medicine rather than on Western medicine for treatment and looked to the family as a primary source of support and recovery. The socioeconomic barriers included a lack of insurance, a lack of transportation, and financial concerns. Immigrants lacking finances were concerned that their monetary status meant they were receiving inferior treatment at county hospitals.

Harmon, Castro, and Coe (1996) asked a community-based sample of Hispanic women about their knowledge, beliefs, and behaviors regarding cervical cancer. The women experienced attitudes of fear and fatalism toward cancer. Huerta and Macario (1999) and Solis (2004) also found that Hispanic women had fear of and fatalistic attitudes toward cancer. Such results have implications for educational and support programs for health care professionals who serve this population.

The preceding studies showed numerous factors that can impede good cancer care, including support groups, for Hispanics. Carpinello (1995) focused on advantages of having a Hispanic self-help group. Initially, the group members did not know how to communicate in English, yet a part of the group's goal was for the participants to learn the English language and be able to participate in the

self-help group. One outcome of the group was that the members were able to have relationships with other people and job status through intercultural exchanges.

Another exception to the idea of underrepresentation of minorities in support groups is the Brown et al. (2002) study showing that most socioeconomically disadvantaged Mexican Americans had the highest attendance rate at diabetes support groups. The researchers suggested attendance was good because the groups served a social function for individuals who did not have many other social outlets.

Ashing-Giwa et al. (2004b) studied understanding the breast cancer experience of women and reported on multiethnic cultural issues that included language barriers and the fact that minority women did not seek a second opinion or question the advice of the physician. This is due to the cultural value of respect for the physician as an authority figure. The participants in the study said the health care system contributed to treatment delays, which subsequently caused participants to be unfamiliar and distrustful with the health care system. The participants also noted they had less control over their medical care and were less inclined to participate as health care consumers. Essentially, the participants stressed a need for more affordable and accessible health care. They felt that it was the responsibility of the health care system to become more culturally responsive to minorities by increasing staff diversity and being more knowledgeable about community resources and psychosocial service partnerships or programs. It is likely many of the preceding attitudes contributed to the facts

that minority women were diagnosed with more advanced disease and experienced greater morbidity and mortality. Finally, the women believed that cancer was caused partially by a stressful life and was controlled by having a positive attitude, which they believed was critical to overcoming the cancer and had numerous cultural manifestations. The participants discussed attitudes of gratitude and faithfulness in overcoming the disease process. The researchers posited that minorities' challenges to treatment included language barriers, cultural factors related to beliefs about the illness, gender roles, and family obligations, for example, self-sacrifice. These women expressed that central to their way of coping was a background in spiritual beliefs. In addition, the women had fatalistic attitudes toward cancer in general and viewed cancer as a death sentence. They believed cancer diagnosis was willed of God, a punishment from God, or the woman's fate, including the outcome of the illness being in God's control. Many had a strong belief in the power of prayer and thought their spiritual beliefs were more important than help from their health care providers. The factors need to be evaluated in order to understand why some Hispanics women choose to not participate in ICSGs.

Though a Hispanic self-help group can have benefits, these Hispanic-specific studies also showed numerous factors can interfere with Hispanics using a support group. A study on Hispanics' attitudes toward ICSGs is needed to determine whether these and/or other factors influence support group participation in the online milieu.

HISPANICS IN RESEARCH STUDIES

In addition to a lack of Hispanics in face-to-face support groups and Internet support groups, a concurrent problem is the challenge of recruiting the Hispanic population in any research, including nursing studies (Gilliss et al., 2001). Gilliss et al. remind us that Section 492B of the Public Health Service Act includes guidelines to advance the inclusion of women and minorities in research. The researchers also emphasize that the Hispanic populations have oftentimes been described as being unaware of the possible benefits of research participation. This is important to this study as there might be a correlation of Hispanics not participating in online support groups similar to Hispanics not participating in research studies. Ashing-Giwa et al. (2004a) revealed that minorities are difficult to contact and are often unwilling to participate in research studies. In addition, Durant et al. (2007) posit that ethnic minority groups have been underrepresented in research compared to their burden of disease and their representation in the U.S. population. However, Brown et al. (2002) found that culturally appropriate recruitment techniques increased minorities' involvement in research. Naranjo and Dirksen (1998) suggested the Hispanic population remains understudied and underserved. In their study dealing with the recruitment and participation of Hispanic women in nursing research, they found women who refused to participate in the study stated their primary concerns related to the influence of family members, a recurrence of emotional stress, and a loss of health benefits.

Ashing-Giwa et al. (2004a) studied a multiethnic sample of breast cancer survivors and noted it was difficult to contact and recruit minorities for their

research study. Among the sample, only 26% of the Hispanic American women were likely to agree to participate in the multiethnic survivorship and quality-of-life study. The researchers also discovered that 21% of the Hispanics in the study lived below the poverty level. In addition, the study showed culture impacted the health-related beliefs and attitudes including spirituality and faith, beliefs about cancer, language, acceptable means of communication, and attitudes toward disclosure. Further, the ethnic minorities, especially those with low socioeconomic status, were more likely to be excluded from participation due to comorbid conditions, particularly if the inclusion criteria were defined very narrowly. The researchers also discovered that there was a major challenge in the languages the research and minority groups used. Many times, the non-English-speaking participants are excluded from research studies due to the costs of translating and administering the study. Using bilingual researchers should help alleviate the language problems, but in some settings, bilingual health care staff is paid more, thus adding to the cost of the study.

Keller, Gonzales and Fleuriet (2005) emphasized the importance of including cultural values into the recruitment of Hispanics. For example, the cultural values of familialism or family obligations; *simpatico,* or respectful interactions; *confianza,* otherwise known as support and trust; and *respeto,* or respect, are important ingredients in the recruitment of Hispanics for research studies. Their study dealt with issues of recruitment and retention of minority women participants in an exercise program to reduce obesity. Other factors that they cite as hindrances to Hispanic participation include: language barriers, family

and community as gatekeepers, and the lack of trust in both the researchers and the research process itself. Still, other factors that were highlighted included: a lack of transportation, interference with work, family obligations, financial costs, burdensome procedures, a lack of flexibility among the investigators and in the intervention protocol, difficulty in scheduling appointments and cumbersome record-keeping requirements.

The studies show the difficulty of recruiting Hispanics for studies, but online studies were not addressed. A study on Hispanics' attitudes toward ICSGs would help determine how an online group might influence such barriers to participating in research and whether other factors might influence participation online.

HISPANICS IN THE UNITED STATES

Each of the demographic characteristics in this discussion may affect the qualitative nature of interactions and results the feminist researcher seeks to obtain from Hispanics.

Hispanic Population Growth

Hispanics comprise the largest minority group in the United States (U.S. Census Bureau, 2004). Because *Hispanic* is not a race, a Hispanic can descend from a variety of races, including white, black, Asian, American Indian, or mixed (by race, African Americans make up the country's largest minority). During the 12 months preceding July 1, 2004, the Hispanic population grew at more than three times the rate that the total U.S. population grew (U.S. Census Bureau, 2004).

By mid 2050, the nation will have 81 million Hispanics; they will compose 24% of the nation's total population (U.S. Census Bureau, 2004). Two of the primary factors for the rapid growth of the U.S. Hispanic population include higher birth rates and rapid immigration from South America, Central America, Mexico, and the Caribbean. Among U.S. citizens and immigrants of Mexican derivation, the population doubled between 1970 and 1980 and doubled a second time by 1990. Also, the number of U.S. citizens and immigrants of Puerto Rican and Cuban derivation increased fourfold more than the growth of the rest of the nation (U.S. Census Bureau, 2004).

Legal Immigration Among Hispanics

Almost 3 million legal immigrants from all nations came to the United States between 1980 and 1990. Before 1950, most immigrants came from European nations. However, between 1950 and 1990, Latin Americans took the lead, with nearly 20 million legal immigrants to the United States (U.S. Census Bureau, 2004). Half of the foreign-born Hispanics in the United States arrived between 1980 and 1990, usually because they wanted to be with family or were refugees of political upheaval (U.S. Census Bureau, 2004).

Assuming that immigrants from other nations that have less per capita wealth than the United States generally had less access to computers in their native countries, it will be interesting to see if the rate of computer usage among Hispanic immigrants rises after they have been in the United States for an extended period. Though research about the subject is lacking, the increase might

be partially inferred by measuring rates of computer usage among Hispanics in general.

Locations of Hispanics Nationwide

Ten states contain 90% of the total U.S. Hispanic population. The U.S. Census Bureau (2004) shows that the chief concentration of Hispanics is in the Southwestern United States, mainly New Mexico, Texas, Arizona, and California. (Availability of resources, which may vary by geographic area, may positively or negatively influence usage of Internet resources.) There they are mainly of Mexican derivation. Florida's Hispanics are primarily Cuban, and the Northeast has a mixture of Puerto Ricans and Dominicans. South Americans are mostly located on the East Coast, while Central Americans tend to be found on the West Coast (U.S. Census Bureau, 2004).

Ages of the Hispanic Population

The Hispanic population consists of a larger ratio of young adults and children but fewer elderly than the non-Hispanic population in the United States (U.S. Census Bureau, 2004). Seventy percent of Hispanics in 1990 were under age 35, in contrast to 50% of non-Hispanics. Almost 4 out of every 10 Hispanics were less than 20 years old, unlike the 28% of the non-Hispanics. Only about 5% of Hispanics were 65 or older, in comparison with 13% of non-Hispanics. The report demonstrates a high fertility rate among recent Hispanic immigrants (U.S. Census Bureau, 2004).

This information hypothetically may apply to this study or future research because, like many groups in the United States, overall computer usage among

Hispanics may increase as young Hispanics increasingly use computers for schoolwork and other tasks. This familiarity with computers may increase computer usage later in life, including in cancer support groups. Another factor hypothetically encouraging such usage may occur as the Hispanic population in the United States ages; they likely will follow the trend common among other population groups and develop increased incidence of cancer (American Cancer Society, 2006).

Educational Attainment for Hispanics

Hispanics have achieved limited advancements in education. In 1990, 1 in 11 Hispanics earned at least a bachelors degree, with half of the population earning a high school diploma, and 1 out of 13 graduated from college; 4 out of 10 finished 4 years or more of high school (U.S. Census Bureau, 2004). There are variations in educational progress among the various Hispanic subgroups: 44% of Hispanics of Mexican derivation got a high school diploma or higher, compared to 53% of Puerto Ricans, and 57% of Cubans (U.S. Census Bureau, 2004).

Languages Spoken at Home by Hispanics

The common bond between Hispanics is the Spanish language. Fourteen percent of people in the United States in 1990 spoke a non-English language at home, usually Spanish. Half of those who spoke Spanish at home reported speaking English very well. Among the Dominicans, Central Americans and Puerto Ricans, fewer spoke English very well (U.S. Census Bureau, 2004). As English proficiency increases among Hispanics, computer usage may increase,

especially usage of cancer support groups and other medical resources commonly in English.

Occupations of Hispanics and Non-Hispanics

The proportion of professional jobs and manager positions held by Hispanics was lower than non-Hispanics in 1990. The largest group of jobs taken by Hispanics included technical sales and administrative support, making up about 39% of Hispanic females, while non-Hispanic females took up 45% of such jobs. Managerial positions and professional jobs were held by 12% of Hispanic males; non-Hispanics held 27% of such positions (U.S. Census Bureau, 2004). If Hispanics held more jobs involving computer usage, their computer usage for medical and other personal needs hypothetically would increase.

Poverty Rates for Hispanics

Approximately 2 out of every 10 Hispanic families lived in poverty in 1990, compared with 1 out of every 10 non-Hispanic families. More Hispanic females, children, and elderly were living in poverty than non-Hispanics (U.S. Census Bureau, 2004). Poverty rates varied among Hispanic groups (U.S. Census Bureau, 2004). Increased poverty levels in any group often occur concomitantly with factors commonly thought to inhibit computer use, such as lower education levels and less computer access (Fawcett & Buhle, 1995).

HISPANIC CULTURE

The Hispanic population is a mixture of many nationalities (Marin & Marin, 1991). The term *Hispanic* generally includes all persons from Spanish-speaking countries but does not factor in specific differences in cultural beliefs,

values, education, socioeconomic status, or the influence one country has on another (Campos, 2006). In addition to having an understanding of the socioeconomic characteristics of the Hispanic population, one must become acquainted with several cultural values of the Hispanic population.

Any generalization about a large population comes with a caveat: One must be careful, especially in individual interactions, not to assume all the general characteristics of the Hispanic culture apply to everyone in all Hispanic subgroups. On a larger scale, different Hispanic subgroups can have differences as numerous as those between Hispanics and other cultures. Nevertheless, the overall Hispanic culture has some classic, signature characteristics.

Familism

The family, or familism (Marin & Marin, 1991; Moore, 1970), is important in the Hispanic community. The family nucleus typically consists of husband, wife, and their children (Keefe & Padilla, 1987). The crucial value of familism denotes strong identity and attachment to the nuclear and extended families, as well as loyalty and reciprocity in helping other family members (Marin & Marin, 1991, p. 13; Triandis, Marin, Betancourt, Lisansky, & Chang, 1982). Ideally, the family unit should participate in research involving a patient, in order to promote familism and personal-space values common among Hispanics. A possible explanation for the lack of participation by Hispanics in formal support groups might be related to the cultural value of familism (Marin & Marin, 1993). Weller, Baer, and Pachter (1999) demonstrated family support was vital in adherence to medication regimen. If family support was absent, then the

patients were less likely to be motivated to continue with their proper disease management routine. In a study of quality of life by Juarez et al. (1998), Hispanic cancer patients reported “having their family as most important” for dealing with the cancer. The term *family* referred not only to immediate and extended family but also to those chosen by the patient to be a part of his or her family. Concerning the idea of social well-being, Hispanic cancer patients indicated the high priority of family support for physical and emotional issues. In Hispanic culture, when one family member is ill, the entire family is expected to help. The patients in a study by Juarez et al. (1998) indicated friends and family would help by bringing food and doing chores. Companionship is also an important function of the family (Juarez et al.). Furthermore, Palos (2004) reported Hispanics tend to include the entire family in decision making. Hispanic culture tends to be collectivistic. Family members consider themselves to be enmeshed with the other members of the family in a collectivistic manner (Rogers & Steinfatt, 1999; Sorrell & Smith, 1993). Due to previously mentioned factors, the family may fill the functions that traditional support groups can provide. There is a clear need to further explore this value in this study.

Hierarchical Power

The researcher should be cognizant of and sensitive to hierarchical power and inequality when conducting research with the Hispanic population (Falicov, 1982; Parker & McFarlane, 1991; Portillo, 1990). In this study, the researcher strived to be sensitive to the differences in gender as related to hierarchical power. Additionally, the patient was highly respected as the data were being collected.

Separately, Falicov and Portillo asserted that the family is paternalistically and hierarchically based. A person's age and gender are important components. Men are higher in the hierarchy than women. Older men have more control over younger men and others, as well as more power in decision making. Older women are also higher up in the hierarchy than younger women, but women as a rule are lower in the hierarchy than men. Respect is interwoven in social interactions and is significantly relevant in the treatment of the Hispanic aged population (Cox & Monk, 1993).

Fatalism

Numerous Hispanic groups have a fatalistic view of life and believe that diseases processes are the result of divine interventions (Larkey, Hecht, Miller, & Alatorre, 2001). Though such beliefs might be attributed to religious, not cultural, beliefs, the ingrained influence of the Catholic Church in Hispanic culture may make the origin of such beliefs indeterminable in many cases. Religion and spiritual perspectives are very important in dealing with health issues in this population (Campos, 2006). Zaldivar and Smolowitz (1994) affirmed that the patients in their study believed that they were ill because it was God's will. Such studies help in understanding the importance of discerning the patient's spiritual perspectives (Campos, 2006).

Allocentrism

Hispanics also commonly value *allocentrism* (Marin & Marin, 1991), otherwise known as *collectivism*, which involves the notion of interdependence, conformity, a readiness to be influenced by others, and a willingness to sacrifice

for the benefit of the group (Arean & Gallapher-Thompson, 1996; Marin & Marin). Additionally, trust of group members and friendly interactions are very important qualities of this group (Marin & Marin). The lack of face-to-face interaction on the Internet is not conducive to allocentrism.

Simpatica

Another value involves *simpatica* (Marin & Marin, 1991, p. 12). This cultural norm is characterized by not emphasizing negative behaviors in conflicting situations but establishing positive behaviors in agreeable situations by using smooth, pleasant social relationships in conjunction with personal dignity and respect for others (Marin & Marin; Triandis, Marin, & Betancourt, 1984). Distinctly for Hispanics, the idea of *simpatica,* might involve issues of reciprocity, which might involve compensating the participants, although not monetarily. Reciprocity might be further explained by using the example of a person choosing to participate in the study and in return expecting the researcher to assist them with a problem that they might be currently experiencing.

Power Distance

Sometimes the fear of disagreement in the Hispanic community is linked to an authoritative person having powerful influence (Marin & Marin, 1991). *Power distance,* which Marin and Marin explained is interpersonal power or influence that exists between two individuals. Furthermore, one individual typically has more power over the other as a result of intelligence, money, or education. Thus, as a result of power distance, Hispanics promote deference and respect toward more powerful individuals. In addition, Hispanics tend to support

authoritarian attitudes and fear disagreeing with those with higher power, if only because the less powerful individual can be in a vulnerable position, or undefended against exploitation (Marin & Marin). Dominguez (1996) asserted that in the Hispanic culture, individuals generally hold health care professionals in high regard and view them with honor**.** The researcher should be aware of any formal, respectful distance expected between the researcher and the participant because this power distance can be a barrier in research situations where the participant may feel vulnerable.

Close Personal Space

Close personal space (Marin & Marin, 1991) is another important characteristic. Hispanics are known to gravitate toward a physical closeness to others and desire the one-on-one interaction that this mode of interaction provides, according to Marin and Marin. It is interesting to note how the attitudes toward ICSGs affect this type of one-on-one interaction, typically associated with traditional support group or family support group structures as opposed to the Internet medium of support.

Time Orientation

Another important value is a present-oriented mode of time orientation. This mode may be explained further by characteristics such as a lack of planning for the future, being inefficient, and not being punctual (Marin & Marin, 1991). It will be also interesting to note how this value affects the attitudes of the participants toward ICSGs, which the Internet offers a medium of little

organization, not being as efficient in structure and having a synchronous or asynchronous type of format.

Gender Roles

Gender roles are important for the men and women of the Hispanic population (Marin & Marin, 1991). The Hispanic man is characterized by *machismo* (Marin & Marin, p. 16), which includes being strong, in control, and helping to meet the needs of the family. On the other hand, women are characterized as being submissive and not having power or influence (Heller, 1966). Women's orientation tends to result in women making sacrifices for their families and relatives, sometimes at the expense of their own health needs (Flores & Mata, 1995). The machismo mindset may repress open communication. However, the feminist researcher should encourage women and men to express themselves freely (Oakley, 1981; Tilden & Tilden, 1985). Such practices lead to reciprocal sharing and trust between the researcher and the participant (MacPherson, 1983). Since ICSGs' effect on machismo and some other Hispanic attitudes is largely unknown, this dissertation's study includes such analysis.

Trust and Caring

Another value very important to the Hispanic community is the need for trust, or *confianza*, and personalized caring, otherwise known as *personalismo*, during interactions (Larkey et al., 2001). A person who is ill often tries self-management of symptoms and often consults family members or friends of the family. Only if such advice does not work or if specialized medical intervention clearly becomes necessary, then the person seeks medical attention. Specifically

with personalismo, the individual might expect a higher degree of intimacy with the health care provider. Galanti (2003) found that as the relationship developed between the provider and the client, so did the compliance of the patient with the treatment. Since the trust and caring aspects are demonstrated on a one-on-one relationship, it is interesting to note how these characteristics affect the attitudes toward ICSGs, which do not involve the personal side of trust and caring.

Several cultural values of the Hispanic population have been described. One of the characteristics depicted in this section included *familism* or family ties that bind the Hispanic population. Hierarchical power dealing with the situation where men are higher in hierarchy than women was also discussed. Fatalism, where disease processes are the result of divine interventions and the belief that it is God that wills a person to be ill or well was also addressed. Allocentrism or collectivism and *simpatica* or positive behaviors are yet other cultural factors. Power distance otherwise known as interpersonal power of influence between two individuals and physical closeness were also evaluated. Yet another cultural value of time orientation, explained as a lack of planning for the future and gender roles including *machismo* for males and being submissive for females were assessed. Lastly, *confianza* and *personalismo* known as trust and caring were also evaluated. All of these characteristics oftentimes are known as signature characteristics of the Hispanic population.

SUPPORT GROUP LITERATURE

Support groups have assisted individuals as they cope with the diagnosis of cancer (Weinberg, Schmale, Uken, & Wessel, 1996). Researchers are in

agreement that cancer patients benefit from support group participation (Grande, Myers, & Sutton, 2006). However, there are limited numbers of people who take advantage of the support group structure. (Grande et al., 2006). Grande et al. (2006) found that support group participants were more likely to be female, single, younger, and to have more education and formal support as opposed to non-participants in their particular study. The researchers also go on to say that the individuals who feel supported within their social network or having a confidant might opt to not participate in the formal support group structure. This support might come from family or friends or significant others. Lastly, the scholars agree on the fact that cancer support groups may not be appropriate for everyone.

The support groups may be generally divided into two main categories. Those that are non-directive and professionally led (Hogan, Linden, & Najarian, 2002) and secondly, the directive group intervention type (Fawzy, Fawzy, Arndt, & Pasnau, 1995). These second type of groups oftentimes introduce expert information, education, training, and/or therapy (Gottlieb & Wachala, 2007). Humphreys and Rappaport (1994) reviewed the literature on self-help and mutual help groups. They affirm that the self-help groups are different from the peer and lay services offered by a professional who supervises the group. Myer and Mark (1995) assert that individuals who participated in the support group structure showed improvement in quality of life, coping and affect. Conversely, Helgeson, Cohen, Schulz, and Yasko (1999) found that not all groups benefited from the support groups.

Moreover, other studies that assist in helping to better understand support groups include the following research studies. First et al. (1990) evaluated long-term and immediate effects on coping and psychological distress methods. The evaluation consisted of a 6 week, structured, psychiatric group intervention for post surgical patients with malignant melanoma. Clearly, the results demonstrated that the short-term psychiatric group intervention for the patients with malignant melanoma helped to reduce the psychological distress and increased longer term successful coping

In another study conducted by Fawzy et al. (1995), the researchers reviewed four types of interventions: education, behavioral training, individual psychotherapy and group interventions. The findings highlighted the various options for cancer patients and the psychological and physical health benefits, which aid the patient who has a cancer diagnosis.

Fawzy et al. (1990) reviewed immune measures, in particular with regard to natural killer cells. Based on a six month follow-up after the intervention, it was noted that the killer cells were different than at the beginning of the intervention. Indeed, it was noted that there was an increase in coping and effective status of the patients was improved by the intervention. Thus, there was a positive outcome related to the immunological response and support group participation.

In two seminal pieces of work, Spiegel and Yalom (1978) and Spiegel, Bloom, and Yalom (1981) studied the effects of weekly supportive group meetings, which included women with metastatic carcinoma. In the first study by

Spiegel and Yalom, the researchers were primarily dealing with a group of terminally ill women with metastatic breast cancer. It was noted that the group had a positive impact on the members' families. Non-members of the group were encouraged by the group members to observe the group interaction and benefit from the group participation as a learning experience. Ultimately, the members were able to support one another by using personal visits and would socialize outside of the group therapy sessions.

In the second study by Spiegel, Bloom, and Yalom (1981), the participants were assessed in a one-year, randomized prospective outcome study. The hypothesis of the study stated that the intervention would lead to improved mood, coping strategies, and self-esteem for the individuals in the treatment group. The participants in the treatment group had significant lower mood-disturbance scores on the Profile of Mood States scale and less maladaptive coping responses and fewer phobics than the control group. The results of the study affirmed that supportive group intervention for women with breast cancer had psychological benefits from participating in the support group. It was also during this time frame that cancer was still a hidden and highly stigmatized disease (Gottlieb & Wachala, 2007).

Gottlieb and Wachala (2007) explain that a support group should have two essential characteristics. The first characteristic includes being led by a professional leader and the second characteristic is that the support group should be a planned activity, which involves the sharing of experiences and mutual support among the individuals in the support group. In the support groups, there is

a common exchange of informational support, which includes facts about cancer, treatment and resources available in the community. The researchers also explain that a difference exists between official support groups and self-help mutual aid groups in that the support group structure has a professional leading the group. Furthermore, the researchers reviewed 44 empirical studies and concluded that the type of participants in the studies had a common theme of the characteristics, which included well educated, white, female, middle class individuals who used the services of other community groups and who reported problems more often and had worse mental health. Another finding included the participants preferring physician and nurse led support groups. Typically, 20% of those who were invited to join the support group declined and another 20% of those who chose to attend any group meeting often drop out before the final session or the post-test. Yet other findings from the evaluation revealed that the participants in support groups felt less alone, better understood and more hopeful after their support group participation. Many of the participants longed for the group to continue after the final session. Yet, Ussher, Kirsten, Butow, and Sandoval (2006) found no differences between the professional-led and peer-led support groups. These researchers affirmed that it was not the professional background of the leader that made the difference but instead, whether the group provided a supportive environment, mutuality, and a sense of belonging, and whether it met the perceived needs of those that attended the group meetings.

Researchers found that if the patients received limited psychosocial interventions, they would often look for support from other sources, especially

cancer support groups in order to meet their needs (Ahlberg & Norder, 2006; Evans, 1995). Herrera (2007) studied 8 Latina women who participated in a bilingual breast cancer support group. She discovered that the women benefited from a strong group leader and comfort was felt by the women who were able to speak in their native language. Taylor et al. (1986) stress that the support may come in various modes to an individual. Such support may come from a spouse, children, or other family members, friends, caretakers, community ties or from a structured support group.

Katz and Bender (1976) described key attributes that are found in support groups. The groups are typically, small, and include face-to-face interaction. There is also an importance on personal participation and voluntary attendance. The main purposes of the group is to come together and help solve a problem or assist individuals with coping with an illness and to provide the emotional support during this time. Lastly, Guidry, Torrence, and Herbelin (2005) studied diverse populations and cancer survivorship. They affirm that potential barriers to minority populations participating in research and support groups include socioeconomic status and a lack of resources to take part in the cancer support groups.

INTERNET CANCER SUPPORT GROUPS

Increasingly, the Internet is being used not only as a means to access information but also as a new form of social space in which people may gather mutually and network (Weinberg et al., 1996). Along with the Internet explosion of use, there is emerging a new set of subcultural phenomena that is loosely

referred to as cyberculture (Rucker, Sirius & Mu, 1992; Hamit, 1993; Barlow, 1995; Turkle, 1995). Cyberculture directly relates to the use of computers for communication and business. It also has been associated with virtual communities. The emerging technologies associated with the Internet may be useful for making advances in the field of nursing research and allowing participants to take advantage of online data collection, questionnaires, and support group forums, which are made available through this creative medium (Childress & Asamen, 1998; Crandall et al., 2001; Curl & Robinson, 1994; Fawcett & Buhle, 1995; Fernandez et al., 2004; Forkner-Dunn, 2003).

A major advantage of the ICSGs is that support groups preclude the need for a physical gathering place and the need for participants to journey from their homes to a central site (Finn, 1995; Weinberg, Schmale, Uken, & Wessel, 1995; Winzelberg, 1997).

Finn (1995), using an exploratory research methodology, describes primarily advantages of using a computer-based self help group as a new resource to supplement existing support group structures. He advocates for the use of computer-based self-help groups to use existing telecommunication networks to provide information and support for social problems. A pilot project for sexual abuse survivors is briefly discussed but offers limited explanation for further uses of this type of resource. The advantages of using the computer self help group include decreasing the time and distance barriers, a lack of group size restrictions, an increase in the variety and diversity of the group, anonymity, and an opportunity for expression through written communication. The pilot project is

described with a limited number of participants. Specifically, two participants had used the service but it was noted that six others had shown an interest. There were limitations to the computer self-help group in that there was no mention of any Hispanic participants using the self help group.

Weinberg, Schmale, et al. (1995) describe computer-mediated support groups. An example is provided of cancer patients using the computer mediated support group. The researchers assert that the computer mediated support groups are able to be of benefit to those individuals who are unable to meet in a traditional face-to-face support group. Certain advantages are highlighted as including overcoming the issue of transportation to and from the support group session. Another benefit is having the support group available 24 hours per day. The participants have the advantage of remaining at home and choosing when to participate. Another advantage is that this medium caters to the person who is uncomfortable with the formal group situation. Yet another advantage is the fact that the person remains anonymous while communicating on the system. This often leads to participants being more open to share about experiences. Lastly, for some individuals, writing about the situation was shown to be less distressing as compared to talking about the situation.

Certain disadvantages were also discussed. First, visual and auditory cues were absent during the interaction. A second limitation is the lack of immediate feedback, which is prevalent in a face-to-face support group. Another important factor in using the online system is that the individual must be able to read, write and be able to see the computer screen, type on the keyboard and be able to

follow simplified instructions. Moreover, electricity, telephone connection, and phone service are needed in order to use the computer system. Additionally, one must also be able to pay for the charges incurred by using the system.

A computer support group for cancer patients was used as an example; however, there was not any sociodemographic information available. Therefore, from the example, it was not known if the participants included any Hispanics and consequently, it was not known if these findings might apply to Hispanics. In general, the obstacles to participation for Hispanics would include being able to read and write English if the group was to be mediated by English speaking participants. Another factor would include the issue of whether the Hispanic participants would have the equipment available to use for the forum participation.

Winzelberg (1997) performed a discourse analysis on 306 electronic messages posted to an eating disorder electronic support group. He asserts that electronic newsgroups, which function as self-help or emotional support groups, are oftentimes found on computer networks. The networks are commonly described as electronic support groups. The purpose of the support groups is to offer assistance on psychological and physical concerns. The conditions that are assisted by these electronic support groups vary from abuse to Tourette's syndrome and 12-step Alcoholic Anonymous programs. The members of the electronic support groups formed a "virtual community." A literature review was done on various types of online support groups. It was noted by Winzelberg that no researcher has specifically examined the content of the discourse that occurs in

these groups. A total of 68 women and two men posted 306 messages during the study. Most of the participants were in their teens or early twenties. Of the messages, 37% were posted between 7 a.m. and 7 p.m., 32% were posted from 7 p.m. to 11 p.m., and 31% were posted between 11 p.m. and 7 a.m. Lastly, the author urged caution to be used before recommending participation in the electronic support groups as there might be unhealthy attitudes being perpetuated by the group and to verify all medical and psychological information obtained from the group. An additional comment was made for the participants in this group format to use this type of electronic support as an adjunct to the face-to-face psychological treatment program.

Since there was not any mention of individuals of minority backgrounds, this study offered a very limited amount of information that might be used for the potential Hispanic's view of ICSGs.

Salem, Anne Bogat, and Reid (1997) investigated an online mutual help group for individuals suffering from depression. A total of 553 participants, which included 273 males and 173 females, had 1,863 postings on the online group. The individuals who participated on the online group had communications which were very similar to face-to-face groups. These characteristics included support, acceptance, and positive feelings. Surprisingly, the group was used more by men than women. The limitations of this study were that there was no mention of sociodemographic breakdown of the participants. Lastly, there was not a mention of any Hispanics using the online communication system for this group.

Indeed, the Internet is likely to be a practical and essential device for meeting health care needs in this century (Gustafson et al., 1999). Among persons living in the United States, the majority already has access to the Internet and is using it as a health care source (Gustafson et al., 1998). Current trends in the Internet access and practice suggest that the information superhighway will be available to all members of the population and could replace the television as a source of information and diversion (Mandl, Feit, Pena, & Kohane, 2000). Consequently, current gaps in the delivery of health care services, namely access to informational and emotional support, could be addressed with new technologies that draw upon the strengths of the Internet (Pennbridge, Moya, & Rodrigues, 1999).

In one of the earliest studies of computer-mediated support groups, Weinberg et al. (1996) investigated a computer mediated support group for six breast cancer patients. For a period of three months, the participants were able to read messages posted from one another. None of the participants experienced difficulty in learning how to use the computer and it took approximately one hour each week to use the computer. The primary aim of this study was to determine the feasibility of providing a computer mediated support group for cancer patients. The research questions that were studied included the following: 1) How much time was required for patients to learn to use the computer? 2) To what extent did patients use the group? and, 3) What types of messages did patients send to each other? The race or ethnicity of the participants was not disclosed. The participants were each loaned a computer with a modem in order to

participate in the study. The study concluded with suggestions that the computer-mediated group could offer these patients many of the therapeutic benefits of a traditional face-to-face group.

Computer-mediated support groups were created and operated as an intervention tool by health care professionals. Their structure and often content are therefore managed by their inventors. In contrast, ICSGs typically emerged as grass-roots phenomena, utilizing the servers of not-for profit organizations, or free services available on the Internet, and are more harmonious with the tradition of self-help groups (Fernsler & Manchester, 1997). Perhaps more important, computer-mediated support groups are offered to a narrow number of participants. On the contrary, Internet support groups are without charge and open to participants without restrictions.

Fernsler and Manchester (1997) evaluated a computer-based cancer support network through a descriptive study. The researchers surveyed a non-random sample of 54 participants of 1,500 members of ICSGs. The participants indicated that the most helpful areas of the ICSGs were placing cancer in perspective, obtaining needed information, ability to help others, and keeping in touch with others. The most useful topics included the treatment of cancer and its effects on the family. The participants discovered that that the computer support networks were a tremendous source for information and emotional support. Some of the limitations of the study included cost and time constraints. The implications of the study resulted in remarks by the participants that the needs of the patients and families for continuing information and support in the process of coping with

cancer were greatly needed. Ultimately, the computer-based support networks served as a provision and was helpful for the patients with cancer.

Owen et al. (2003) evaluated the effectiveness for adjuvant psychological treatment for women with breast cancer and the feasibility of providing online support for these women. They postulated that Web-based treatment formats could potentially improve the effectiveness by means of increasing the availability and accessibility of the online support. In this feasibility study, there were two phases that were studied. The first phase involved an assessment of internet access and perceived interest in online support for 136 women with breast cancer. Of the 136 women, there were 84% white and 16% African American women. There were no Hispanic women enrolled in the study. It was noted that the levels of interest for participation in an online psychosocial treatment were associated with age, outcome expectancy, and barriers to suing the Internet. The second phase involved recruitment and changes involved with the recruitment over time in the Internet access. Of significance was the fact that the rates of recruitment were higher when a research study spokesperson was available at the clinic in order to provide information about the treatment. The final results suggested that Internet-based psychosocial treatments, along with some limitations are potentially realistic for increasing the impact of psychosocial care.

Weinberg, Schmale, et al. (1995) investigated the non–face-to-face groups otherwise known as computer or Internet support groups as compared with the traditional face-to-face support groups with six breast cancer patients. Each of the participants was provided with a computer to be used for support group purposes.

In general, the members of the group decided that the support group was helpful. Yalom's (1970) therapeutic factors of installation of hope, universality, group cohesion, catharsis, and altruism were investigated. The results of this pilot provided preliminary information indicating that the therapeutic factors of instillation of hope, group cohesion, and universality were viewed as most active therapeutic factors in addition to the factors most related to the helpfulness of the group. The researchers agreed that the literature supported these same factors were prevalent in both face-to-face and computer support groups. The altruism aspect was found to be unrelated to the helpfulness aspect.

The sample group was very small, and there was no mention of any sociodemographic characteristics mentioned in the study. Therefore, it is not known if any Hispanic participants were included in this study. Lastly, as this was a pilot evaluation, it was recommended that a larger sample be studied for consistency in the future findings.

In summary, the prospective benefits of online interventions have been well documented, and participants have reported very positive perceptions of their involvement in these groups (Owen, Klapow, Roth, Nabell, & Tucker, 2002; Weinberg, Uken, Schmale, & Adamek, 1995). Online interventions may reach a population of patients that are currently underserved by existing services. However, an evaluation of an Internet-based group for Hispanic cancer patients is needed.

Families and Support Groups

Why are Hispanics not involved in formal support groups? To keep the lack of Hispanic participation in perspective, consider that Hispanics are not the only minority group not engaged in support groups. Data on trends in support group formation indicated some improvement in participation has occurred in the very low numbers of groups intended for African Americans (Nash & Kramer, 1994; Wituk, Shepherd, Slavich, Warren, & Meissen, 2000), Native Americans (Burhansstipanov, Lovato, & Krebs, 1999; Daniel et al., 1999), and Hispanics (Guidry et al., 1997; Miano et al., 1996). In addition, Kaskutas et al.'s (1997) population-based study revealed that Hispanic ethnicity was a significant predictor of help seeking behavior.

A possible explanation as to why Hispanics do not attend support groups might be related to the cultural values of familism, personal space, simpatica, and allocentrism (collectivism) (Marin & Marin, 1993). All these values are supported by the nuclear and extended family (Asing-Giwa et al., 2004a; Sabogal et al., 1987). As was explained earlier in the section on familism, families fulfill a patient's needs in ways that make the family function like a formal cancer support group (Rogers & Steinfatt, 1999; Solis, 2004; Sorrell & Smith, 1993).

A very important factor is that a patient's family members might have positive experiences in their own family support group; thus, their experiences might discourage the patient in attending a formal support group because the support is received at home. There has been minimal research done on Hispanic cancer patients' families participating in any kind of support group. Yet, Hispanic

families might benefit from other families in support groups. Discussing caregivers' stress and the benefits of support groups, Garstka, McCallion, and Toseland (2001) stated that caregivers' stress levels are related to their evaluation of the situation, coping behaviors, and perceived social support, but involvement in support groups can help with such problems by developing social support for caregivers, offering them better coping responses, presenting opportunities fore social comparisons to individuals who may be facing greater obstacles than their own, and therefore helping change caregivers' evaluation of the situation. Indeed, the support group structure may reduce stress and improve caregivers' health and well-being (Garstka et al.). Assuredly, these support groups may provide information for caregivers that could help them in coping.

Challenges in Studying Hispanics' Views of ICSGs

Studying Hispanics often can be challenging, if only because such research often requires a variety of methods. For instance, researchers must use culturally appropriate methods (Marin & Marin, 1991; Meleis, 1999; Naranjo & Dirksen, 1998; Rehm, 2003). Marin and Marin's (1991) suggestions for studying the Hispanic population help illustrate one of the methods. First, the study should be based on cultural values of the targeted group. For studying Hispanics and ICSGs, values such as familism, allocentrism, simpatica, power distance, close personal space, time orientation, gender roles, and personalismo should serve as the underpinnings of the study. Secondly, the strategies that comprise the intervention should reflect the subjective cultural characteristics of the group. These characteristics include attitudes, expectancies, and norms about specific

behavior. Lastly, the behavioral preferences and expectations of the group should be addressed.

Social Support

The value of social support for those afflicted by chronic illness including cancer has been well documented (Spiegel, 1995; Komproe, Rijken, Ros, Winnubst, & Hart, 1997; Stewart, 1989; Gotay & Wilson, 1998; Katapodi et al., 2002; Walker, Wasserman, & Wellman, 1994). Spiegel affirms that social support may influence coping style by changing the focus from an uncontrollable primary problem such as advancing cancer to a controllable one such as influencing the effects of cancer, some of which are social and psychological. This affirmation may be extended to the Hispanic population.

Social support has been explored by Frazier, Davis-Ali, and Dahl (1995), who studied the relationship between social support and patient adjustment. The patients who received more accommodating support from their spouses reported being more satisfied with their marriages and reported less depression.

Support groups are one method of enhancing social support (Frazier et al., 1995). The support group phenomenon has been documented in a broad and still expanding literature on support groups, self-help, and mutual aid (Cella & Yellen, 1993; Fobair, 1997; Pillon & Joannides, 1991; Spiegel, Bloom, Kraemer, & Gottheil, 1989). Although the concept of support groups is not novel, study of the topic began only 30 years ago, when increasing numbers of groups were established as part of the human potential and feminist movements (Levy, 1984). Initially, researchers were captivated by the problem-solving focus of the groups

and their obvious predisposition for offering mutual support to those facing similar social issues or health problems not covered by the existing health or social service providers (Katz, 1986). Others studying the phenomenon found that group contribution seems to bring about helpful results by offering information, practical advice, and emotional support (Gottlieb, 1995).

THEORETICAL FRAMEWORK

Based on the literature review presented from a feminist perspective, a theoretical framework was developed to guide the study (Figure 1). In congruence with general principles of feminist philosophy, the researcher assumed a socialist feminist view for this theoretical framework in order to highlight the Hispanic viewpoint as it pertains to the group's oppression by the cultural norms of this society. In addition, the voices of the Hispanic participants were heard pertaining to their attitudes toward ICSGs.

The theoretical framework (Figure 1) consists of two major constructs: Hispanic cultural attitudes and their use of the ICSGs. This dissertation studied certain Hispanic culture-specific attitudes because numerous studies lend support to the idea that those attitudes may influence Hispanic cancer patients' attitudes toward ICSGs. The research questions of this study were designed to explore the Hispanic cancer patients' culture specific attitudes toward ICSGs. Culture-specific attitudes include familism, hierarchical power, fatalism, allocentrism, simpatica, power distance, close personal space, time orientation, gender roles, and trust and caring. The attitudes were evaluated for an exploration of

differences in attitudes between those interested and those not interested in ICSGs.

The purpose of this theoretical framework is to describe the relationship between the main construct of the study, which is the Hispanic patients' culture-specific attitudes, and the other construct, the use of ICSGs. In this relationship, the influences of contextual factors and Hispanic culture that ultimately lead to the use or disuse of the groups are considered.

To examine the relationships between the constructs, this study employed qualitative methods in order to explore the Hispanic cancer patients' culture-specific attitudes toward ICSGs.

SUMMARY

A description of the theoretical background to the study and a review of the literature related to ICSGs were provided. The theoretical background of the study, which includes feminism in general, diverse feminist thoughts, and the feminist approach taken in the study were discussed. Then, the critical review of the literature, which included native-born patients and Hispanic immigrants in the United States, an overview of Hispanic culture, Hispanics' cancer experience, and ICSGs potentially relevant to Hispanics' views on ICSGs, was discussed. The challenges in studying Hispanics' views of ICSGs were also evaluated. Finally, an explanation of the theoretical framework developed for this study was provided. Chapter 3 provides an explanation of the methodology for the study.

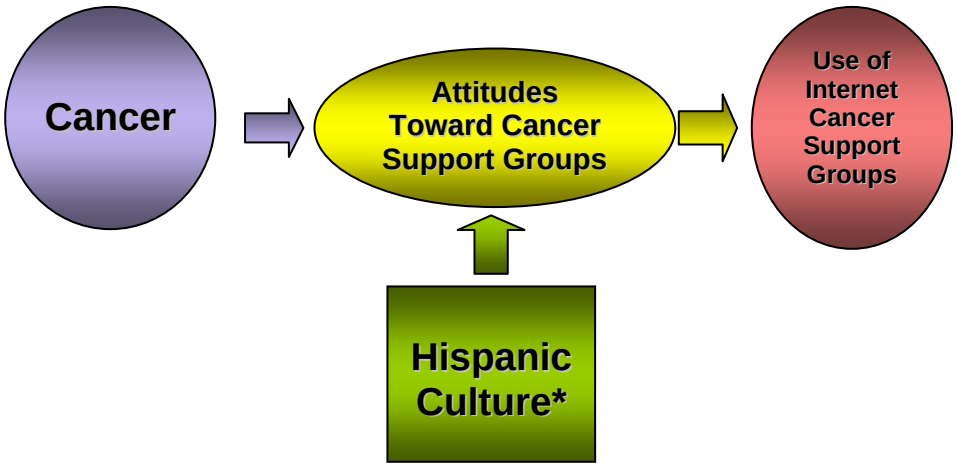

Figure 1. Theoretical basis.

* Familism, Hierarchical Power, Fatalism, Allocentrism, Simpatica, Power Distance, Close Personal Space, Time Orientation, Gender Roles, Trust & Caring

Chapter 3: Methodology

The purpose of this chapter is to describe the methodology for this dissertation study. This chapter contains a description of the study design, settings and samples, instruments, interview format, data collection procedures, translation of data, human subject protection, and procedures for data analysis. The chapter also includes the strategies used to ensure rigor of this study from the feminist approach.

FEMINIST QUALITATIVE STUDY DESIGN

Because of the limited information on Hispanics' attitudes toward Internet support groups, a qualitative study was conducted. Feminist qualitative studies have historically been done to highlight diverse and oppressive situations of underserved populations (Olesen, 2005; Crotty, 1998; Hall & Stevens, 1991); this study also uses a feminist qualitative study design using thematic analysis because Hispanics also face a system of inequalities (Olesen, 2005). More specifically, this dissertation uses a *socialist* feminist view because Hispanics as a group are oppressed by the cultural norms of society.

The feminist approach to research brings several perspectives that are useful in many instances, including the Hispanic group in this study. Rubin and Rubin (1995) assert that feminist critical research respects both the researcher and the participant in the collaborative research process and includes cultural distinctions, which allow for emotions and expressions to be revealed. Since this study concerns the emotions, expressions, and other aspects of a distinct cultural

group, namely the Hispanics, a feminist research perspective works well. Im (2007) says the feminist approach is more open and less structured, which helps involve the Hispanic participants in their viewpoints on ICSGs. This study incorporates other aspects and the ensuing benefits of feminist research. For instance, Creswell (1998) says the feminist method yields research that is transformative, avoids objectification, and is collaborative and nonexploitative between the researcher and the participant. To stress the benefits of avoiding objectification, note that Sampselle (1990) says individuals' value to society should coincide, not solely on their biological and sexual characteristics, but with their capacity to contribute. Moreover, the feminist methodology also lends itself to allowing the participant to express personal emotions and reactions to the research questions, as opposed to the traditional positivist approach of eliciting a typical *yes* or *no* answer. Such methodology has been described as being gentler and also one that listens more to the participant.

Parker and McFarlane (1991) describe this methodology as being nonhierarchical because the interviewer is allowed to invest a personal identity in the relationship and to encourage a collaborative and open relationship between the researcher and the participant. DeMarco et al. (1993) assert that the research focuses on reflexive, not hierarchical, relationships between the researcher and the participant. Also, the participant is treated more like a human, as opposed to a laboratory specimen. In essence, all participants are given a voice for those who have been silenced, and empowerment is given to the interviewees (Rubin & Rubin, 1995; Keddy, 1992). Assuredly, the researcher's questions allow openness

and loose structure in order so the researcher and participants can learn about each other during the research process. As the participants' own views, perspectives, opinions, interests, and experiences are prioritized, the relevance, otherwise known as the research questions that can assist with the participants' own issues and interests, is revealed and studied (Hall & Stevens, 1991; Im, 2007).

Moreover, another goal of the feminist approach is to build a relationship between the researcher and the participant and have each contribute to the criterion of rapport, which involves discovering words and concepts needed to express themselves and engage with one another (Rubin & Rubin, 1995; Hall & Stevens, 1991).

Feminist researchers (Ford-Gilboe & Campbell, 1996; Hall & Stevens, 1991; Olesen, 2005; Wuest, 1993; Im, 2007) have labeled this connection between the researcher and participant as an intersubjective relationship because both the researcher and the participant share in the creation of the data. Wuest (1993) further suggests that the research findings should be communicated with the participants and that the ensuing discussion should include implications for participants' personal growth and directions for change in the political or social order. The findings of this study will be communicated with the participants at the completion of the study.

Hall and Stevens further elaborate on this by explaining that a research goal is to provide an explanation of what participants need concerning the studied phenomena which affects their lives and is seen through their eyes. Thus, in this

study, the participants were asked for their opinions regarding their attitudes toward ICSGs.

Rubin and Rubin (1995) elaborate on the roles of the interviewer and the study participants regarding culturally specific methods. These researchers say benefits occur when the interviewer and the study participant have a shared culture. For example, a Hispanic researcher should interview a Hispanic participant in order to help bridge cultural chasms. Yet another recommendation is that the researcher refrains from dominating the conversation and allows the participant to feel in control instead of being a research case. The interview should be similar to normal conversation that allows the participant full freedom of expression. When the researcher asks selective questions in a way that allows for a distribution of power both on the part of the researcher and the participant, the researcher achieves the feminist-research goal of researcher and participant learning about each other (Dyck & McLaren, 2004; Borbasi, Jackson, & Wilkes, 2005; Harding, 1987). Furthermore, Olesen (2005) suggests that feminist qualitative research methodology is valuable for explorations into subjective issues and interpersonal relations, and this type of research remains highly diversified, enormously dynamic, and thoroughly challenging (p. 235). Parker and McFarlane (1991) assert that the research focus of a feminist study has the inherent ability to personally benefit the researcher and the study participants. As the results of this study with Hispanics unfolded, the general and culture-specific benefits of the feminist approach became even more evident. Finally, the feminist qualitative design is being used in this study in order to highlight the limited

information on the Hispanics' attitudes toward ICSGs. The study respected the participants' viewpoint in an open and less structured format with a collaborative and open relationship between the researcher and the participants.

SETTING

Thirty self-identified Hispanic patients with cancer were recruited through a cancer care clinic in the Austin vicinity. The outpatient clinic provides services, which include prevention, diagnosis and medical treatment, for adult cancer patients from throughout the central Texas region. In addition, the clinic provides services to many underserved patients, including Hispanics without any type of medical insurance coverage. The clinic is centrally located next to a major trauma center. Hispanics comprise 40% of the total patient population treated at this particular clinic.

RESEARCH PARTICIPANTS

The study included 30 participants. The inclusion criteria for the participants were (a) self-reported cancer (participants from all types of cancer were included) patient at least 21 years old; (b) able to read and write English or Spanish; (c) Hispanic as the self-reported ethnic identity; (d) willing to participate in a 60 minute telephone interview; and (e) current patient at the cancer clinic.

Researchers are in agreement that there are no set criteria or rules for sample size in qualitative research (Sandelowski, 1995; Coyne, 1997; Brink, 2001; Byrne, 2001; Polit, Beck, & Hungler, 2001; Fossey et al., 2002; Higginbottom, 2004; Polit & Beck, 2004; Tuckett, 2004; Collins et al., 2006; Kearney, 2007). While guidelines have been made available for the qualitative

method of inquiry, strict sample size numbers have not been offered for feminist qualitative research. Onwuegbuzie and Leech (2007) offer the following summary of sample size suggestions: Creswell (1998) has recommended that qualitative researchers should (a) study one cultural-sharing group in an ethnography, (b) examine three to five cases in a case study, and (c) explore the narrative stories of one individual in narrative research (p. 197). In addition, Creswell (1998) recommended interviews with up to 10 people in phenomenological research and interviews with 20–30 people in grounded theory. Qualitative researchers do agree on the gold standard of saturation and thus, this **is** the guideline standard for sample size that the researchers employ. Morse (2000) has suggested that the number of participants needed depends on various factors. For instance, if the participants are good informants and are able to reflect on their experiences and communicate well by interviewing several times, the study may be achieved with a smaller number of participants. She further says that for interviews with two to three unstructured interviews per person may need 20 to 30 participants. However, since this study used structured interviews, the higher end of the suggested sample size number is used. Thus, 30 participants or until data saturation was achieved was considered adequate for the study.

The study was reviewed by the Institutional Review Board of the cancer care clinic and The University of Texas at Austin, and permission to speak to the participants was obtained from the clinic. For the recruitment process, the 30 participants were recruited at the cancer care clinic. All participants were selected using a purposive sampling method and were chosen as they were receiving

treatment at the cancer care clinic or were in the lobby waiting to be evaluated by a medical provider. After securing permission from both the IRB and clinic staff, the researcher went to the cancer care clinic and approached the clinic staff. The staff made the flyers available to the potential participants. If a potential participant expressed an interest in participating in the study, the participant was referred to the researcher. The researcher approached the patient in order to begin to establish a relationship and also to schedule an appointment for the researcher to contact the participant by telephone. The informed consent sheet was then provided to the participant. The researcher and the participants exchanged phone numbers in order to make appropriate communications. In order to provide privacy to the participants in the waiting room and infusion rooms, the telephone approach was chosen.

INSTRUMENTS: SOCIODEMOGRAPHIC AND SCREENING QUESTIONS

The following sociodemographic data were collected, assessed, and summarized to characterize the study participants (see Appendix A):

1. To measure sociodemographic characteristics, eight questions (8 variables) on age, gender, education, religion, marital status, work, family income, and access to health care were used to measure and describe the sociodemographic characteristics of the participants.
2. To measure self-reported ethnic identity, there were 10 questions (10 variables) including self-reported identity, country of birth, length of stay in the United States, and degree of acculturation. When the country of

birth was not the United States, degree of acculturation was measured using six questions about length of stay in the United States and preferences for food, music, customs, language, and close friends. Preference for foods, music, customs, language, and close friends were measured using a Likert scale 1 to 5 (1 = *exclusively own ethnic group*, 5 = *exclusively American*). These five questions were adopted from the Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA) (Suinn et al., 1987; 1992) and modified to measure degree of acculturation among multiethnic groups. Validity and reliability of the original SL-ASIA have been supported among Asian populations (Suinn et al., 1992).The reliability and the validity of the modified SL-ASIA has been supported in the Decision Support Computer Program with cancer pain patients (Im et al., 2007). In order to further measure acculturation in the entire sample, the Deyo Brief Language-Based Acculturation Scale was used (Deyo Diehl, Hazuda, & Stern, 1985). The scale was developed to quantify English use among Mexican Americans and was constructed from four brief questions that had excellent scaling characteristics by Guttman Scalogram Analysis in two independent data sets. The construct validity was established by significant associations of the scale with the following: ethnicity, place of birth, generation within the United States, and the type of neighborhood. According to Deyo, the scale is valid, reliable, and

capable of distinguishing meaningful subsets among the Mexican American population (Deyo et al., 1985).

3. Self-reported disease status was measured by using one item rating general health (1 variable) and five items about cancer (diagnosis of cancer, length of time since diagnosis, primary cancer site, type and stage of cancer) (5 variables), previous current medical treatments (for example, radiation therapy, chemotherapy, surgery and hormone therapy) (1 variable), and medication use (1 variable).

INTERVIEW FORMAT: INTERVIEW GUIDELINE/PROTOCOL

A literature review was conducted in order to develop questions that might solicit a discussion concerning attitudes toward ICSGs. An expert panel consisting of seven oncology nurses reviewed the following questions for refining the questions. The members of the panel were chosen from the cancer care clinic due to their oncology expertise. A final member of the panel was also an oncology nurse working in the community health arena and dealt with a large Hispanic cancer population. The questions were reviewed with each member of the expert panel for validation and/or changes to the questions. Based upon the feedback from the members of the expert panel, the questions that were ambiguous were removed from the list and only the questions where all of the members were in agreement were kept. Ultimately, the final questions were reviewed with the expert panel, and all of the members of the review panel were in agreement that the questions were appropriate to be used with the proposed

participants. The developed questions were reviewed for preliminary clarity as an initial inquiry, and a more in-depth refinement of the questions was done after the Institutional Review Board gave its approval. The questions were reviewed a second time with the expert panel for any further modifications. Additionally, the questions were tested with the first two participants from the clinic in order to evaluate for any further changes to the questions. These interviews were used in the data analysis sample since there were no significant changes in the questions made subsequent to these interviews.

The questions are:

1. When you have questions about your medicine or your disease, who do you talk to? For example, do you ask your spouse, children, boss, priest, or friends? Who else do you ask? Why or why not?
2. Explain any type of support that you receive from other sources, such as your family, church, support groups, etc.
3. What things help you to decide to be in a support group? Is it more comfortable to be in a group of women or men only? Why or why not?
4. How would you feel about trusting others in the support group with details about your disease?
5. What are your feelings about others treating you with respect and dignity during a support group and do you feel that the support group would benefit you?

6. Who would you need permission from in order to attend a support group or an Internet support group? Describe the type of transportation that would be available to you in order to get to a support group.
7. Tell me about your experience with a personal computer.
8. Sometimes people that have the same disease communicate by using the computer to help and support one another. One example of this is an Internet cancer support group. If you had access to a computer and if someone showed you how to use the computer, would you be interested in communicating with other people by using a computer? Why or why not?
9. If you had access to a computer, would you have a preference for the information to be in English or Spanish? Why or why not?
10. If you had a computer, would you be interested in learning more about your disease by information on the Internet about your disease? Why or why not?
11. Anything else that you would like to add about your feelings toward Internet cancer support groups?

DATA COLLECTION PROCEDURES

The participants were cancer patients and were recruited from a community cancer clinic. The inclusion criteria were reviewed with the participants, and permission was obtained from the IRB at the cancer care clinic

in order to perform the study at the clinic. Oral and written consents were obtained from the participants.

After IRB approvals from both The University of Texas at Austin and the cancer care clinic were received, the researcher went to the cancer care clinic in order to recruit the participants for the study. The clinic staff was instructed on the purpose and aims of the study. In compliance with the IRB standard, a flyer and an informed consent sheet were drafted by the researcher in order for the staff and the researcher to make available to the potential participants in the study. Additionally, a ten-dollar gift certificate to Wal-mart was mentioned in the flyer and offered to the participants.

The staff directed the researcher to any potential leads for recruiting the participants for the study. The potential participants were in the waiting room of the clinic or in the infusion room receiving cancer treatments. Commonly, in the infusion room, there are many patients who are receiving intravenous cancer treatment and are available for up to four hours to speak to researchers. It is during this time that the researcher became acquainted with the potential participants. The researcher approached the potential participants and explained the research project by using the information sheet. Those participants who were interested in the study exchanged telephone numbers with the researcher. The researcher then explained the informed consent sheet to the participant. After returning home, the participants then used a telephone to call the researcher directly. Once the participant called the researcher, the researcher gave the participant a brief review of the research project, and verbal and written consent

was obtained. If the participant did not call the researcher, then the researcher called the potential participant the following week. Even though face-to-face interactions are more congruent with the feminist approach, the decision was made to use phone interviews in order to provide privacy since the participants were typically in an open room while receiving chemotherapy or in the waiting room.

The researcher asked the participant which language was more comfortable for the participant, English or Spanish. The researcher collected the data in English or Spanish, based on the preference of the participant. Data for this group of participants were collected by the researcher by telephone and recorded by using audio taping. Audio taping was done by using a Digital Voice Tele-Recorder (RadioShack) system. In order to protect the anonymity of each study participant, each interviewee was assigned a fictitious name and interviewed by telephone for approximately 60 minutes. The sociodemographic and survey questions were asked and recorded by using a hard copy of the questionnaire. The questionnaire was filled out by the researcher according to the answers from the telephone interviews. The self-identity questions were asked, followed by the screening questions. Subsequent to this, the Deyo Scale was administered by the researcher by using a pen-and-paper method. Then the interview questions followed, and a tape recorder was used for the session in order to record the responses to the questions. In order to factor in any potential fatigue challenges on the part of the participant, the researcher strived to be very cognizant of any types of cues of fatigue—for example, long pauses, etc.—and

allowed for brief rest periods. At the conclusion of the interview, the researcher obtained the name and the address for the participant in order to mail a ten-dollar Wal-mart gift card to the participant for completing the study.

TRANSLATION OF DATA COLLECTED IN SPANISH

The data collected in Spanish, which is known as the source language, was translated to English, the target language. The data collected in English did not require any type of back-translation. The strategy for translating the data was the back-translation method (Brislin, 1986). Maxwell (1996) suggests that back-translation entails a three step process. The data are translated from English into the target language; a different translator translates that version back to English, and finally an English-speaking person compares the original test with the back-translation. For this study, the process of translating the data was as follows. Initially, the data were collected by interviewing the participants once and by recording the conversation on an audio tape; a bilingual investigator, who is literate in both the Spanish and the English languages, collected the data. The transcription process is as follows: the researcher became very familiar with the data by playing the tape several times in order to listen carefully to the content and the questions that were being asked of the participants. Memos were written and reviewed in order to describe the interview context. A copy of the recording was made to provide a back-up. The tape was transcribed into the Microsoft Word program in a form to be ready for analysis. The tape was transcribed word for word from the interview, and the transcription was then checked against the tape for accuracy. Researcher comments were placed on the text by using bold font in

order to separate it from the actual interview. All pages were numbered sequentially, and each page was coded with the interview number. The data were printed, and a back-up file was created. For the conversations recorded in Spanish, the researcher translated the data to English in writing and then allowed another doctoral student or researcher to back-translate the data to Spanish. Then, the back-translation followed, and the resulting data was compared. Any discrepancies were then analyzed. The corrections were negotiated by the translators, and the best English version was selected. Lastly, the recorded tapes will be stored in a locked cabinet for 10 years and then will be destroyed.

HUMAN SUBJECT PROTECTIONS FOR AN EXEMPT STUDY

An application was made to the IRB at The University of Texas at Austin for permission to proceed with the study. There are no known risks associated with the study since the data have no identifying information about the participants. The participants' identities, including names and contact numbers, were asked. The participants were informed that data collected through the taped interview would remain confidential. Participants were also informed that there would be no disclosure of an individual participant's responses outside the research study. In addition, the researcher mentioned to the participants that there might be a possibility of discomfort or inconvenience due to the telephone interviews. If the participant reported any discomfort or inconvenience, the researcher allowed the participant to discontinue the interview if he or she so desired.

To ensure confidentiality, only the investigator and the translator had access to the data. The printout of the transcripts remained in the possession of the researcher at all times, and the transcripts were locked in a file cabinet for security when not in use.

PROCEDURES FOR DATA ANALYSIS

In order to understand the interactions between the researcher and the participants, a qualitative thematic analysis as described by Graneheim and Lundman (2004) was used for this study.

First, the quantitative data of the participants were analyzed using descriptive statistics (e.g., frequencies, means, standard deviations) to characterize sociodemographic profiles and self-reported ethnic identities. Second, thematic analysis according to Graneheim and Lundman (2004) began with deciding the unit of analysis. The unit of analysis was made up of the words from the interviews about the participants' attitudes toward ICSGs. After that, the meaning unit from the participants was documented and coded as a coding unit, which was evaluated for condensation. It was at this point that the codes, categories, and themes were created. Next, the categories or codes of content that have commonalities were identified, and then the categories were finalized and themes were extracted by linking the categories.

The interview data were explored for content that examines an understanding of the Hispanic cancer patients' culture-specific attitudes toward ICSGs. The data were analyzed for similarities and differences between those who expressed an interest in ICSGs versus those who did not express an interest

in them. The focus of this study was on the exploration of the Hispanic cancer patients' attitudes toward ICSGs.

RIGOR OF THE STUDY

To promote rigor throughout the study, the researcher used feminist principles of rigor. Feminist perspectives stress four crucial features related to the rigor of a research study (Hall & Stevens, 1991): (a) reflection of concern for the Hispanic participants' own experience and the experience of the Hispanic group, (b) gender and cultural relevance of measurements by allowing the Hispanic women and men in the study to share their own respective experiences, (c) meaningful interactions between the researchers and the participants by collaborating with the participants, and (d) a scrutiny of the researchers' assumptions and perceptions during the data analysis process (also scrutinized by the researcher's dissertation committee chairs). This study employed all four principles.

By minimizing the infringement of the researcher's own perceptions, assumptions, and interpretations, this study maximizes the reflexivity of the Hispanic men and women as they share their personal situations regarding their attitudes toward ICSGs. Unlike the emphasis on reliability and validity in conventional quantitative research, feminist researchers highlight the credibility and adequacy of the study findings. To improve the credibility of the researcher's interpretations, feminist researchers emphasize checks and balances through significant interactions with the participants (Hall & Stevens, 1991). The participants should themselves share and validate the research data (Campbell &

Bunting, 1991). In this study, credibility was partially accomplished by sharing the preliminary findings with the dissertation chairs and will be further ensured by sharing the findings with the participants at the completion of the study.

In this feminist perspective study, the standards of rigor in feminist research as employed by Hall and Stevens (1991) were used to guide the study. The first standard—*dependability*, or the degree to which data changes over time—was ensured by examining the methodological and analytic decisions that were evaluated for the topic questions analysis. Second, in order to ensure *reflexivity*, a record of the research and memos was evaluated. Third, *credibility and relevance* were evaluated by asking the participants to provide feedback on the topic questions and to interact closely with the researcher during the data collection phase of the study. Finally, *adequacy* of the study was ensured through constantly evaluating the research method, aims, research questions, design, scope, analysis, conclusions, and impact of the study within the social environment throughout the data collection and analysis process. Such strategies contributed to the rigor of the study's qualitative approach and reflexivity of its analysis and narrative data among the Hispanics and their attitudes toward ICSGs.

SUMMARY

The main purpose of this chapter was to describe the methodology for the study. A description of the methodology, plus methodological information about this study, was included. The study design, settings and samples, instruments, interview format, data collection procedures, translation of data, human subject

protection, and procedures for data analysis were discussed. Lastly, the rigor of this study conducted from the feminist approach was described.

Chapter 4: Findings

The purpose of this study was to explore the attitudes of Hispanics toward ICSGs and possible reasons for a lack of participation in ICSGs. This was achieved by evaluating interview data collected on 30 Hispanic cancer patients and analyzing the data by using thematic analysis. The research questions that guided the study were, "What are the Hispanic cancer patients' attitudes toward ICSGs?" and "What are the differences in attitudes toward ICSGs between participants who are interested and those who are not interested in participating in ICSGs?" The purpose of the analysis that follows is to explain the Hispanic participants' attitudes concerning ICSGs. The 30 Hispanics who were interviewed voluntarily shared their attitudes toward cancer support groups and toward ICSGs. The demographic characteristics of the participants are presented, followed by the thematic analysis of study data.

Sociodemographic Characteristics of the Participants

The participants included persons diagnosed with cancer, who were at least 21 years of age, had a self-reported Hispanic ethnic identity, and were able to read and write English or Spanish. However, 50% had a language-based Deyo acculturation scale of 1.0, which indicated low acculturation and suggested the persistence of Spanish language use. A majority of participants wrote and spoke Spanish better than English. Based on other characteristics of the majority, a typical participant was a middle-aged, married, Catholic woman diagnosed with breast cancer. Though born in Mexico, she equally preferred Mexican and

American food. Her family had a low, insufficient income, but she did not work outside the home. Additionally, she at least had a high school education. There was a split between some enjoying American customs and their own Hispanic customs versus some enjoying mostly their own ethnic customs. A great majority enjoyed close friends being from their mutual ethnic group. The mean age of the participants was 43.63 years (SD = 7.99) with a range of 31–61 years of age. The median annual family income was $18,070 (range = $10,400–$150,000) (Table 1).

Table 1

Background Characteristics of Participants (n = 30)	*n* (%)
Gender	
Female	26 (86.7)
Male	4 (13.3)
Religion	
Protestant	8 (26.7)
Catholic	19 (63.3)
Others	3 (10.0)
Marital status	
Married	20 (66.7)
Divorced	2 (6.7)
Single	8 (26.7)
Employed outside the home	
No	20 (66.7)
Yes	10 (33.3)
Music preference	
Mostly American music	1 (3.3)
Equally American and own ethnic	17 (56.7)
Only own ethnic	12 (40.0)
Education (most advanced level)	
Elementary school	2 (6.7)
Middle school	7 (23.3)
High school	13 (43.3)
Partial college	3 (10.0)
College graduate	5 (16.7)

Table 1 (*cont*)

Characteristics	*n* (%)
Income satisfaction	
Totally insufficient	21 (70.0)
Somewhat insufficient	5 (16.7)
Sufficient for essential needs	3 (10.0)
More than sufficient	1 (3.3)
Born in the U.S.	
Yes	2 (6.7)
No	28 (93.3)
Health status	
Unhealthy	1 (3.3)
Tend to be unhealthy	5 (16.7)
Do not know	1 (3.3)
Tend to be healthy	14 (46.7)
Very healthy	9 (30.0)
Cancer site	
Breast	24 (80.0)
Colon	1 (3.3)
Uterine	1 (3.3)
Stomach and liver	1 (3.3)
Testicular	1 (3.3)
Throat	1 (3.3)
Thyroid	1 (3.3)
Cancer stage	
Stage 1	2 (6.7)
Stage 2	11 (36.6)
Stage 3	5 (16.7)
Stage 4	5 (16.6)
Unknown	7 (23.3)

Table 2

Sociocultural Characteristics of Participants (n =30)	*n* (%)
Racial group	
Mexican	27 (90.0)
Others (1 Peruvian, 1 Columbian, 1 Honduran)	3 (10.0)
Food preference	
Mostly American food	1 (3.3)
Equally American and own ethnic food	23 (76.7)
Exclusively own ethnic food	6 (20.0)
Customs	
Mostly American customs	2 (6.7)
Equally American and own customs	14 (46.7)
Mostly own ethnic customs	3 (10.0)
Only own customs	11 (36.7)
Ability to read and speak English	
Read and speak English better than another language	3 (10.0)
Read and speak another language equally as well as English	7 (23.3)
Read and speak another language better than English	20 (66.7)
Ethnic origin of close friends	
All Americans	1 (3.3)
Americans and own ethnic group	20 (66.7)
All own ethnic group	3 (10.0)
Score on Language-Based Acculturation Scale	
0	7 (23.3)
1	15 (50.0)
2	7 (23.3)
3	1 (3.3)

MAJOR THEMES

Overview

Thematic analysis of the 30 participants' comments revealed four themes: the need for a strong social network, varied attitudes about information access, concrete barriers to obtaining support, and the need for respect and empowerment. The themes intertwine somewhat, as do some of the items delineated under each theme.

The Need for a Strong Social Network

Study participants usually realized the need for a strong social network, but their varying definitions of *strong* add many dimensions to this theme and provide insight on their perceptions of online and in-person support. Thus, this theme has five elements: (a) differences in online and face-to-face communication; (b) loneliness, isolation, and some antidotes; (c) existence or lack of familial support; (d) spiritual support; (e) informal, occasional support, a minor element. All of these subthemes fostered the need for a strong network. It became obvious that there was a need for communication and this was demonstrated in the form of a strong social network.

Differences in Online and Face-to-Face Communication

The participants expressed that they valued and preferred the form of support that the face-to-face group had to offer, as opposed to an Internet support group, because the face-to-face group, though somewhat structured, was less

structured, more free flowing, and more interactive than an ICSG. Those components of the face-to-face group facilitated the desired social networking.

Sixteen of the participants had begun to attend a breast cancer support group that covered many topics. Through their comments, participants revealed that components of the face-to-face group encouraged social networking they desired. Discussing in-person support groups, one participant said, “I like the person-to-person support groups because I am a people person. Nothing can replace the actual person that you see. You can see their emotions.”

Another participant said, “You have people that feel like you owe them something. And on the computer, you cannot do these one-on-one things. And, whatever you think, they really don’t know me [online].”

Thus, the face-to-face groups more closely resembled the informal chatting popular among many Hispanics. Several participants highlighted what else they valued in the group. One said, “I like coming to the support group, where we can visit with one another.”

Another commented, “The person-to-person … I mean, what if you want to give someone a hug or something like this? Also, there are feelings that you can share with face-to-face and put all together and the communication that you have with each other.”

Conversely, some participants preferred the computer groups so they could keep their anonymity. As one participant said, “This would be a good opportunity to use the Internet support groups since I did not want for anyone to

see me in this condition [loss of hair and eyebrows]. You do not have to show your face in public."

Loneliness, Isolation, and Some Antidotes

The Internet helped fulfill participants' desire for social networking: Participants enjoyed having 24-hour availability of human contact via the Internet, receiving assistance for depression problems, being able to easily contact someone else with the same condition, and getting support online because they did not want to be seen in public due to the side effects of the cancer treatment.

Loneliness and isolation often, but not always, occur simultaneously. Some study participants discussed the two separately. Usually, the lonely person also felt isolated, but for some people, isolation itself was a problem. Some study participants said they felt like they were the only ones going through the cancer experience. Sometimes physicians aggravated isolation by not providing information. One participant stated, "The doctors let you go without this information and leave you very ignorant about what is going on with the breast cancer, and they leave you with nothing. No one told me about the support groups."

To help combat isolation and loneliness, many participants expressed interest in using the Internet for a variety of reasons. One patient explained:

> [Internet] chat groups are open 24 hours per day. Lots of times the people that are going through cancer are innocent of what is going on, and they have to do so many things. When the person is at their house, normally the person has depression. The chat rooms are good and provide motivation. The support groups, the chat groups, can be helpful to these persons that are suffering from the disease, and this is a lot more convenient.

Another participant pointed out:

> Sometimes because of medication, one cannot sleep for eight continuous hours per night. Then, it would be very convenient for the person to wake up early in the morning, get on the chat group, and find someone else that is going through the same thing … This would be very good to find someone else on the chat group and begin to discuss the same problems.

Finally, another participant requested to be included in ICSGs because she did not want to be seen in public during her treatment phase:

> People were telling me when I was going through the treatments that I needed to be in church because these were hard times for me. I did not have any hair or eyebrows, and I did not want to go to church during this time. The only thing that I knew was that when I was ready, I was going to go to church on my time. I kept telling them, 'Don't you understand that I do not want to go to church now?' I was feeling well physically, but emotionally, I was not feeling well because I did not have any hair or eyebrows. I wanted some time to myself since I was in this condition.

Existence or Lack of Familial Support

Some participants clearly valued an effective social network, but they had no interest in the support groups because they could rely on their family and friends—that is, their traditional social supports—to be an informal support group structure. These participants expressed strong identities and attachments with their nuclear and extended families and had feelings of loyalty and reciprocity in being helped by their family members. The family members who provided the support included spouses, children, grandchildren, and siblings. Because the family was present, the participants said they were motivated to continue with their proper disease management routines and would usually complete their prescribed cancer treatments. Often, the family members would be included in making decisions about the cancer patient's care.

Participants usually held the family unit in high esteem, and for many, this cultural characteristic was an integral part of their support system. Many participants were attached to their nuclear and extended families and were very loyal to their family members, even when they were not part of participants' support system. Among those with non-supportive families, one participant said, "My family would also all help me at first, but then as the time went by, they did not check up on me as frequently." Another added, "They [family] know [about the cancer] … we talk now and then but not very often about my disease."

Another participant offered the following: "Sadly, I did not receive any type of support from my family.… It did not interest them. Perhaps, like me, they had never heard of this illness before. Maybe they had never heard of this illness, and they do not know anything about this type of problem."

Conversely, comments by three participants illustrate the broad range of support provided by some families. One participant said,

> I talked to all of my family. When they tell you about the cancer, you think that it is over for you and that this is your final time on earth, right? That this will be the end of you… My family encourages me a lot. They have helped me with this illness, and even now, they have really helped me so much. All of my family, they are all able to encourage me a lot.

A second participant said, "I never did get depressed. I did feel sad at first. But I had so much support from my family. Then I did not think that it was necessary to go to a support group because I have my family and they help me with all of the decisions."

A third participant said,

> My wife and family tell me to continue forward, and they encourage me so much. My support comes from my family. But I have never been in a

> situation where I had to go and look for the support. I did feel sick when I was going through the treatments. I was sick physically, but emotionally I was doing fine and never reached a point when I needed the other help from another group.

Spiritual Support

Spiritual support might replace or decrease the need for any type of secular support group for some participants. A secular support group provided spiritual support for one participant. Spiritual support came from formally organized churches, more informal spiritual groups, individual relationships with God, and combinations of those categories. Prayer often was identified as a type of support in all those categories. Wherever and however they found a supportive social network with a spiritual aspect, patients' comments showed they valued such networking.

The church and other spiritual sources provided the strong support of a social network for some participants. Among these participants, wide variances occurred in their sources of spiritual support, their preferences and aversions to face-to-face and Internet support groups, and their need for a secular support group.

Discussing the support from formally organized churches (recall that 63% of the participants were Catholic), one participant said, "The people from the Catholic Church, they are there to try and help me, and they do help me."

Another person expressed that the sisters [women from the church] from the church would pray for her daily, and that church members treated her with respect, trust, and caring. She said, "When I get with the brothers [men from the

church] and sisters from the church, they treat me with dignity. The brothers and sisters from my church, they give me a lot of support."

Discussing spiritual support from more informal spiritual groups, one participant said, "I get support from the Christian community [not just at church]. This community is able to give me moral support, psychological, and spiritual support."

Another participant commented, "For two months, every Saturday, we would get together and pray. This was another type of medicine for me."

Among those combining spiritual support from churches and more informal groups was this participant, who said, "I have great support from my church because I am a Guadalupana, and I am in prayer groups, and my friends go to different churches where there are prayer groups. You know a lot of prayer."

One participant said she gained spiritual support from several sources, including her secular cancer support group:

> My support groups that I belong to is with a Christian community, the church, and various persons in the [cancer support] group have had the same disease. Or, they have had cancer. And now they are survivors thanks to the medical attention that they receive. They have been able to be treated quickly, and it is very important. It all depends on how they have been cured. And these people have the testimony that this helps them. And this is the basics of what helps them, and then it encourages one with moral and psychological support and spiritual support. This is what gives people the moral support to follow ahead.

Strongly illustrative of the solo approach to spiritual support, one participant said:

> Since I have not had the opportunity to go to a formal support group, the only support group that I have is with God. Basically, it is not that I am a religious person, but at the times when I have needed someone, it has been

> God. I have gone through many crises, and I have always gotten my comfort from reading the Bible or things like this.

Informal, Occasional Support

Informal, occasional conversations among cancer patients sometimes produced supportive interactions. Such interactions, loosely defined as a group process, occurred between study participants and non-participants.

One participant summarized these informal groups:

> Sometimes when you get chemotherapy and you are there with the other patients, you talk to them and the nurses. This is kind of a form of a support group. You know, when you are there with the others that are going through the same types of treatments and you all talk with one another. This is what happens in a regular face-to-face support group.

Because these groups were so informal and occasional, they did not influence participants' choices about more formal support groups of any kind and were not identified as a major source of support.

Diverse Attitudes Regarding Information Access

Attitudes about information access were mixed. Some participants had positive attitudes about learning information about their disease and in learning how to obtain it via computer. However, some participants did not want to obtain information, and some had negative attitudes only about learning to use the computer.

Interest in Computers and Online Information

Several of the participants expressed an interest in ICSGs and in reading information on the Internet about their disease. Many participants not only wanted to learn more generally about the personal computer, they also expressed interest

in requesting to be taught how to use one. Additionally, they were interested in the Internet and how to use it. Ultimately, they expressed an interest in learning more about ICSGs.

Participants' interest in computers coincided with interest in obtaining information and support about their disease. Participants' interests included reading online information in order to get tips on self-care, nutritional care, preventative care, and their medication programs. One participant said, "This is the point about going on the computer. You can go on there 24/7 and find information that you are looking for, and this is what I like about using the Internet."

Another participant said:

> I could be of help to other people on what I have lived through; I would like to be able to share with other people. And also, I would like to be informed about my condition and how I can help myself better by reading the information on the Internet. Because of what I have gone through, it would be helpful to be more informed so that I could help more people.

Disinterest in Computers and Information About Cancer

Conversely, some participants simply did not want to learn more about their condition; so the computer was unappealing. Others expressed negative feelings only about learning to use the computer. Some participants stated that their disinterest in computer-related resources stemmed from reasons including feeling intimidated by even the idea of using a computer. Numerous participants mentioned the difficulty of computers. It was not uncommon for participants to rely on others for online information. Participants often did not say why they relied on others, but participants answering other questions often mentioned the

difficulties of learning the computer and of gaining computer access. In addition, some participants preferred face-to-face interaction over anything done online.

Those relying on others included these participants. One said, “My child is the one that has a computer. I do not know how to use the computer.... I think that I will let my son continue to use it.” Another participant said, “I do not want to learn how to use the computer or the Internet. I would want for someone to give me the information.” Some participants did not want to know about the side effects of their cancer treatments. Some participants were dealing with their fatalistic attitudes toward cancer. For example, some participants expressed that they did not want information from the Internet about their breast cancer because such information might aggravate their concerns about experiencing a recurrence of cancer. A participant said, “For me to have cancer is to have death. Being told that I had cancer was the same as death for me. I guess it is the power of suggestion. I feel that if I was not to know about it, then it would be better for me.”

Other participants were interested in learning more about the state of their disease, but their concerns about recurrence limited their quest for information. As one participant stated,

> I would like to learn more about my illness. But if I was to get a lot more information about my illness, then I might have too much information, and I do not want to think a lot about my illness. If I am only thinking about my illness, then I feel like I might get sick again with the cancer. If I keep thinking about the illness, then I think that the cancer might come back to me. And I do not want to have so many suggestions about the cancer and so much information about the cancer.

There was agreement that the Internet offered a great deal of information, but participants did not want to know too much about cancer, and they were haunted by memories of their past experiences with cancer treatment and the possibility of reliving this same experience again. A participant said, “I think that it is good to have information about the disease. I know that there is a lot of information on the Internet. At times, too much information on the Internet, and I do not want to have any suggestions about the cancer that would come to me.”

Concrete, Non-Attitudinal Barriers to Obtaining Support

Though many participants had an idealistic interest in learning more about the ICSGs and were potentially open to future participation, many participants faced two major concrete barriers: They did not own a computer, and they had transportation problems that limited their access to a computer and other support.

Lack of Computer Ownership

As previously mentioned, a large majority of the participants had lower socioeconomic status, that is, a median annual family income of $18,070. Therefore, it is not surprising that most participants reported they did not have a computer. Some had limited access to the computer system at their place of employment. This fact of a lack of computer ownership, though simple, is a major barrier to obtaining information and support online. The participants expressed the following: “I would be interested in learning how to use the computer and about Internet cancer support groups. If I had a computer and someone was to show me, then I would be interested in it. But, I do not have a computer,” and “I

would like to be able to buy a computer and learn how to use the computer. It would be very important for me to learn how to use the computer."

Transportation Problems

The very common lack of transportation obviously would hinder participants from going to a computer to participate in an ICSG. Transportation problems also were a concrete barrier because they kept study participants from participating in a face-to-face group, and many participants considered such try-out participation essential before considering an ICSG.

Lower socioeconomic status also limits transportation options for many people. So, though some participants had relatives and friends with computers, the participants often said they had transportation problems, which would limit easy access to those computers and others in the community.

When participants were asked about their attitudes toward ICSGs, many first wanted to experience a face-to-face support group but were not able to attend because of a lack of transportation. Thus, the lack of transportation was a factor influencing attitudes about ICSGs in this population, but it was not a major factor because most people wanted to experience an in-person group first, and no one knows what their opinions about ICSGs would be after experiencing an in-person group.

Comments from participants with transportation problems included the following:

> I would like to attend a support group. I would like to get to know other cancer people and talk about the experience. I understand that they say things like everybody goes through the same things and also different

> things. I would like to learn about these things. I would like to learn about the differences of opinion about the disease.

Another stated, “I am having a problem with transportation because we had a car accident. I do not have a car now.”

Along the same lines, another participant said, “I have a problem with transportation. I do not drive. This is why I do not commit myself to going to a support group. I do not want to commit myself to this. I cannot do this.”

The Need for Empowerment

This theme includes discussions of (a) the empowering use of Spanish in support of cancer patients and (b) empowerment and group leaders. These subthemes emphasize the relationship between the use of Spanish and how group leaders were used in order to promote the need for empowerment in this group of participants.

The Empowering Use of Spanish

The participants affirmed their culture’s credibility by seeking the use of Spanish, which is the primary expression of their culture, in important settings such as health education materials and support groups. Perhaps more importantly, participants were better able to check the credibility of oral and written communication done in Spanish. For example, some study participants wanted more online usage of the Spanish language, including in ICSGs, in face-to-face support groups, and with information about cancer. Participants said use of their primary language, Spanish, could better help them understand information, establish trust, be accepted, and be able to be believed. As mentioned above, that

66% read and spoke Spanish better than English. Also, 50% had a language-based Deyo acculturation scale score of 1.0, which suggested the persistence of Spanish language use among these participants. They further expressed that using Spanish would make them more confident about dealing with their illnesses and more willing to trust others with their feelings about their disease. Affirmatively, they believed that their Spanish-speaking support network was one of the reasons that they had survived, and that the support structure was crucial to recovery because of the different levels of support for moral, psychological, and spiritual areas. Also, they felt that they could persevere and be more accepted, as they knew that they would receive some help through the support group.

Three participants offered their thoughts about the need for resources in Spanish. One said,

> One of the things that is very important relates to language. For example, if the person that comes to the support group is Latino and they find other Latinos in the support group, then they would be more willing to participate and be accepted, especially for the people that speak Spanish only and that do not speak English. This is the way that the person can express themselves. This is what gives confidence to the person.

Another participant said, “The Latino community does not participate in Internet support groups because I have never seen a support group on the Internet for the Latino community that is in Spanish. Also, they do not have time.”

A third participant said,

> The Latino community sometimes does not have access to the computer and is not familiar with using the computer. Most of the people use the computer for e-mail, text messaging, but not with cancer support groups. They do not participate in the Internet support groups because the information is not in Spanish.

Empowerment and Group Leadership

Empowerment was also demonstrated by a strong support group leader. For example, the leader of the support group in which some of the interviewees participated was a Hispanic layperson with appealing characteristics. Her ethnicity and use of Spanish undoubtedly helped participants, but, having previously discussed their preferences for the use of Spanish, participants stressed the leader's other characteristics when discussing her.

The leader had several positive characteristics. She was Hispanic and spoke the Spanish language fluently. Additionally, she had been diagnosed with breast cancer several years ago, had received treatment, and is a survivor. She showed respect and caring by personally inviting women to the group; all of the women who participated in the study and who had a breast cancer diagnosis had some type of interaction with the leader. The participants related to her well, and they showed her much deference and respect. They all spoke highly of her and valued their time with her during the support group meetings. In addition to personal interactions, the leader would invite experts to provide information and explanations about medical conditions. Assuming that knowledge is power, the concrete information and the caring, nurturing atmosphere empowered the leader and participants.

Information proved popular among participants like these two. One participant said, "They [group leader and her assistants] are all angels to us because we are able to communicate with them. They give us information about everything. They help us with the doubts that we have."

Another participant commented:

> I feel good because, like I said, whatever question we have, we get answers. And we get information. I talk to other people, and this feels good, and it is very beautiful to have this kind of information that they can give us. They also tell us about their experiences. I do not feel alone.

SUMMARY

Out of the of the 30 participants' comments, four major themes arose, though the themes and their elements readily intertwine. Themes are the need for a strong social network, varied attitudes about information access, concrete barriers to obtaining support, and the need for respect and empowerment. Since social support is such an individualized, multi-source issue, that theme has five elements: (a) differences in online and face-to-face communication; (b) loneliness, isolation, and some antidotes; (c) existence or lack of familial support; (d) spiritual support; (e) informal, occasional support, a minor element. Participants had mixed attitudes about information access, a theme which includes participants' overall open, positive attitudes toward ICSGs. Positive attitudes were more common and included wanting to learn about their disease and wanting to learn how to obtain information and support via computer. However, some participants did not want to obtain information, and some had negative attitudes only about learning to use the computer. One of the simplest but most important themes involved two major, concrete barriers to information access: Many participants did not own a computer, and they had transportation problems that limited their access to a computer and other support. The theme involving the need for respect and empowerment discussed the empowering use of Spanish in

support of Hispanic cancer patients and empowerment via the group leader, who was Hispanic.

Chapter 5: Summary, Conclusions, and Recommendations

A discussion of the findings for each of four themes that became apparent from the research is included in this chapter. Next, the limitations of the findings and a discussion of the conclusions are included. Finally, recommendations for nursing theory, practice, and research as suggested from the study's findings are included.

DISCUSSION OF THEMES

Four themes emerged from comments by the participants. The themes, which were somewhat intertwined, were the need for a strong social network, diverse attitudes about information access, concrete barriers to obtaining support, and the need for empowerment. All of the themes had cultural relevance to the Hispanic population.

Theme: Need for a Social Support Network

The value of social support for those afflicted by chronic illnesses, including cancer, has been well documented (Spiegel, 1995; Komproe et al., 1997; Stewart, 1989; Gotay & Wilson, 1998; Katapodi et al., 2002; Walker et al., 1994). Further, this study was in agreement with the work of Frazier et al. (1995), who explicated that support groups were one method of enhancing social support. As for the subtheme about differences in online and face-to-face communication, the literature showed mixed preferences for the two types of communication among varied populations, including women with lupus erythematosus (Mendelson, 2003), psychotherapy patients (Taylor & Luce, 2003), and

perimenopausal women with migraines (Moloney et al., 2003). Some participants in this study attended a face-to-face cancer support group, and most of them said they preferred support from a face-to-face group as opposed to the idea of an Internet support group. The face-to-face group, though somewhat structured, would be less structured, more free flowing, and more interactive than an ICSG. Those components of the face-to-face group facilitated the desired social networking. As revealed by Guidry et al. (1997), social support networks assisted participants with the continuation of the cancer treatments. However, participants' objections to an ICSG were only theoretical because they had not tried a Hispanic ICSG, which did not exist at the time of the study.

The subtheme of loneliness and isolation, along with some antidotes, included findings from participants who experienced one or both situations. For these people, the Internet often helped fulfill their desire for social networking in a variety of ways. Participants enjoyed having 24-hour availability of human contact via the Internet, receiving assistance for depression problems, being able to easily contact someone else with the same condition, and getting support online because they did not want to be seen in public due to the side effects of the cancer treatment. The literature mentioned similar uses of the Internet, such as its 24-hour availability (Kouri et al., 2006), as well as its usefulness in treating depression (Houston et al., 2002) and giving social support to the homebound (Martin & Youngren, 2000). Davison et al. (2000) studied patterns that emerged with online support groups; the participants in the Internet support groups had the highest levels of support activity with several types of disease conditions, which

included breast cancer. Another example was Wright's study (2000), which explicated the advantages and disadvantages of the social support network. One advantage was the use of online communication, which resulted in a lack of stigmatization that the participants otherwise felt from others when communicating within a group. Additionally, Taylor and Luce (2003) affirmed that computer-assisted therapy appeared to have been equally effective as face-to-face treatment for anxiety disorders and depression. In another study, Klemm and Hardie (2002) examined depressed patients with cancer who used Internet support groups instead of face-to-face groups. This study supported the same finding.

Regarding the subtheme about the existence or lack of familial support; most participants, even if they had unsupportive families, usually held the family unit in high esteem, and for many it was an integral part of their support system. When families were supportive, participants said they valued an effective social network, but they could rely on their family and friends; so the participants were uninterested in support groups. Marin and Marin (1991) also discussed a very similar situation, a strong social network with these characteristics: strong identification with the nuclear and extended families, attachment and loyalty to the family, and reciprocity in helping other family members. Thus, utilizing the family as an informal support group structure has been reported in previous studies (Sabogal et al., 198; Siantz, 1994; Ashing-Giwa et al., 2004a). Palos (2004) reported that Hispanics tended to include the entire family when making decisions; in this study, this same finding was noted.

Although many studies have discussed the advantage of familial support, there is little information about the effects of a lack of family support. The study's findings showed that some participants did not have familial support, but they still showed attachment and loyalty to their families. Thus, this finding adds new information to the literature on the family structure. Perhaps an explanation for this finding might be that participants without familial support still showed respect and deference for their family members in an effort to maintain allocentrism (Marin & Marin, 1991). This is a hallmark cultural characteristic of the Hispanic population, which puts the family before individual interests.

The fourth subtheme, spiritual support, is well documented in the literature (Ashing-Giwa, et al., 2004b; Culver et al., 2002; Mickley & Soeken, 1993; Siantz, 1994). In a study about Hispanic culture, Juarez et al. (1998) noted that religion contributed significantly to the management of cancer pain. Campos (2006) found that religion and spiritual perspectives were very important to Hispanics in dealing with health issues. In this study, the church and other spiritual sources provided the strong support of a social network for some participants. Among these participants, wide variances occurred in their sources of spiritual support, their preferences and aversions to face-to-face and Internet support groups, and their need for a secular support group. Nolan et al. (2006) described spiritual issues that arose online among pancreatic cancer patients. Spiritual issues included spiritual convergence, reframing, suffering, hope, and acceptance of the power of God and eternal life. In this study, 63% of the participants were Catholic, and several participants specifically mentioned that they favored

spiritual support. Agreement was made with Ashing-Giwa et al. (2004b), who revealed that spiritual beliefs were more important than help from participants' health care providers. This would help in understanding why some Hispanics in the study would choose not to participate in ICSGs.

Although the subtheme of informal, occasional support is deemed minor because of its unreliable, unpredictable, and irregular nature, this subtheme added new information to the current literature on the use of face-to face support groups by Hispanics in a hospital-based setting. Contrary to Camosy's (1996) findings, where Hispanics were not prevalent in the hospital-based system, this study found that Hispanics in a structured support group sometimes became involved in informal, hospital-based support groups. For example, the active participants were involved in the breast cancer support groups and the informal chemotherapy infusion rooms where they were getting support from each other during the chemotherapy infusion times.

Theme: Varied Attitudes About Information Access

Participants' interest in computers often seemed influenced by how much they were interested in obtaining information and support relating to their disease. However, those participants who were interested in obtaining information often relied on others to get the information online. Though participants most often did not directly say why they were uninterested in computers or why they relied on others, the literature and participants' answers to other questions provided some possible clues.

Relying on others often was the easiest way to obtain online information. Some participants said they ignored the computer because they preferred face-to-face interaction over anything done online. That preference did not hinder participants in the face-to-face support group from obtaining online information because the leader and probably others in the group were an easy conduit for such information.

Participants often mentioned the difficulties of learning the computer and of gaining access to one. Similar attitudes appeared in the literature. For instance, Bacon et al. (2000) said reasons for not participating in ICSGs included experiencing technical problems with computers and a lack of technical skills.

Some participants said they felt intimidated by even the idea of using a computer. The literature documents a potentially related fear. Harmon et al. (1996) revealed that there was a prevalence of fear and fatalism toward cancer. Additionally, Huerta and Macario (1999) and Solis (2004) found that fear and fatalistic attitudes occurred with cancer conditions. Personal feelings of fear and fatalism likely would be a hostile environment for learning a new, difficult subject such as how to use a computer, which might arouse its own set of associated fears and fatalism.

Theme: Concrete, Non-Attitudinal Barriers to Obtaining Support

Even though participants often expressed interest in an ICSG, it is not surprising that their interest was only theoretical for many reasons. For instance, the median annual family income was $18,070, so a large majority of the participants expended most of their time and money on basic resources and did

not have a computer. This situation was not unique to the group studied. Recall that 2 out of every 10 Hispanic families lived in poverty in 1990 (U.S. Census Bureau, 2004). Increased poverty levels often occurred concomitantly with factors commonly thought to inhibit computer use, for example, lower education and less computer access (Fawcett & Buhle, 1995). Participants indeed reported transportation problems that would limit computer access. Another economic barrier, not mentioned by participants, is the cost of Internet access (Klemm et al., 1998). As Hacker and Steiner (2002) revealed, a digital divide existed between the groups with computer access and those who did not have access.

Participants did not mention barriers to using a computer at work for Internet access, but their lower socioeconomic status might indicate scarce access to workplace computers, especially consoles with enough privacy for exploring sensitive personal health issues. Lack of transportation also limited some participants' ability to participate in a face-to-face support group, and many considered resolving this initial step of participating in a face-to-face support group essential before they considered doing so. Their limited participation in a face-to-face support group was not surprising. Taylor et al. (1986) reported that individuals with low socioeconomic status and minority individuals were underrepresented in cancer support groups. Even in this era of less expensive, more widespread computers and online access, there was no change to the fact that, as Fawcett and Buhle reported in 1995, poverty rates for Hispanics correlated with less computer access, whether due to scarcity of computers, lack of transportation, or other hindrances of lower socioeconomic status. Bacon et al.

(2000) affirmed that the lack of transportation problem presented a major problem for some families.

Theme: Need for Empowerment

This theme covers (a) the empowering use of Spanish in support of cancer patients and (b) empowerment and group leadership. These subthemes helped show the relationship between the use of Spanish and how group leaders were used in order to fulfill the often unspoken needs for empowerment and respect in this group of participants. This applies to the part of the sample who attended the face-to-face support group. Importantly, the group leader was a participant in this study.

To empower someone is an inherently respectful action. The participants who attended the support groups had the support group leader who used Spanish to communicate with them; she could have been intrinsically empowering them because speaking Spanish showed respect for participants' personal abilities and culture. Likewise, receiving respect was empowering, so respect and empowerment were inextricably intertwined, at least in this setting.

Speaking Spanish might not convey respect in some settings, but the Spanish-speaking leader of the support group showed her respect for group members in many ways, including speaking Spanish with them.

In the literature, language barriers have been a challenge for Hispanic patients in securing appropriate treatments and communicating with physicians (Ting-Toomey, 1999; David & Rhee, 1998; Ashing-Giwa et al., 2004b; Ellington, Sahami, & Mooney, 2003). Herrera (2007) discovered that the women in her

sample group benefited from dealing with women who were able to speak their native language of Spanish. For participants in this study, benefits of using Spanish included affirming their culture's credibility by seeking the use of Spanish, which was the primary expression of their culture, in important settings such as health education materials and support groups. Perhaps more important, participants liked the idea of being better able to check the credibility of oral and written communication done in Spanish. Many participants said using their primary language, Spanish, could help them better understand information, establish trust, be accepted, and be able to be believed.

The subtheme of empowerment and group leadership was illustrated by the leader of the support group for some participants. In one of several examples participants gave about the leader's actions, the leader would invite experts to provide information and explanations about medical conditions. Assuming that knowledge is power, the concrete information and the caring, nurturing atmosphere in the group empowered the leader and participants. In a reciprocal relationship, they empowered and honored her for her empowering actions toward them. Bacon et al. (2000) suggested that communicating with others having similar experiences was the greatest motivating factor for participation in the group. Breast cancer treatment is an obvious example of a similar experience; it is an interesting thought, but only hypothetical, that mutual empowerment was enough of a shared experience to be a major motivator for participation in the group.

LIMITATIONS OF THE FINDINGS

Participants' opinions about ICSGs were not based on experience. Some participants did communicate with other people online, but there was no Spanish-speaking group, which participants said was a very good idea.

The group studied consisted of 30 people. In this group, the leader of the face-to-face support group was a participant in this study. Further, 16 of the participants came from this support group. Some of the potential problems are as follows:

- More than half the participants were in a face-to-face Hispanic support group they liked very much, but they had no experience with an ICSG.
- The support group leader did not have a random sample but actively recruited for her group. For the study, all but six participants were recruited from one breast cancer clinic.
- Almost half the participants were healthy (and were presumably visiting the clinic for reasons such as check-ups). Ideally, the sample would have consisted of larger numbers of healthy and actively ill participants.
- Most participants were females of Mexican origin who spoke Spanish better than English and had insufficient incomes.

Simpatica, the Hispanic cultural characteristic of establishing smooth, positive behaviors and pleasant social relationships (Marin & Marin, 1991), might have influenced interactions between the researcher and the participants. Perhaps participants gave what they thought were socially acceptable answers and answers

the researcher wanted. The researcher encountered conversation that included much detail about attitudes.

CONCLUSIONS, RECOMMENDATIONS, AND IMPLICATIONS

The findings of this study may help provide some insights for researchers and health care providers interested in starting a Hispanic ICSG. Some influences on Hispanic ICSG usage may not change, such as the widespread, strong preferences for social support from families and people in spiritual settings. However, one goal of an ICSG could be to augment instead of replace support. For example, an ICSG could have a spiritual basis. Or there might be several ICSGs—one each for patients, families, and supporters such as friends from church. ICSGs also could target people without these supports.

Some issues will cause attempts to create a Hispanic ICSG to be aborted in the early planning stages. Lack of computer access should be addressed early, especially if the target population has lower socioeconomic status. Lack of computer knowledge is another sizable problem. The rapid pace of technological advances may help those problems if computers quickly become much easier and much less expensive. Another potentially large issue, lack of transportation, could affect patients' ability to attend computer literacy classes, find computer access, and much more.

Yet for existing fans of the Internet, such as the lonely/isolated in the study, an ICSG could improve the online experience by giving participants a well-moderated forum containing good information. Having an ICSG in Spanish would be a major enhancement. Importantly, there is an indication that individuals

should be assessed and that general assumptions should not be made regarding Hispanics' inclinations regarding support groups.

Basic education and graduate nurse education should address the facts that, for the most part, Hispanics preferred to receive their emotional and psychological support from the extended family. Therefore, an ICSG operator might suggest that the Hispanic members receive their preferred method of support but help educate them regarding alternatives such as the support group structure in case there is an interest in it.

An effort should be made to better educate primary care providers (physicians, nurse practitioners, and physician assistants) on referring Hispanics who have been diagnosed with cancer to a cancer support group at a much earlier time in their diagnosis. With proper education methods, this might help to spur the curiosity of the Hispanic population about face-to-face support groups and might eventually lead to their participation in ICSGs.

As Carpinello (1995) shared on the advantages of having a Hispanic self-help group in which the members did not know how to communicate in English, a part of the group's goal was for the participants to learn the English language and be able to participate in self-help groups and have intercultural exchanges. Similarly, Hispanics who are limited in the English language could learn the language better in an effort to communicate with all non-Spanish speakers. As English proficiency increases among Hispanics, computer usage may also increase, especially usage of cancer support groups and other medical resources commonly available in English. Yet another strategy, as revealed by Ashing-Giwa

(2004a), was to use bilingual researchers in order to help alleviate the language problem.

As stated earlier, ICSGs have been shown to be beneficial in helping patients with coping strategies and psychological well-being (Cella et al., 1993). Future studies should help to identify other factors in Hispanics' preference for face-to-face support groups and in reasons they might start to accept ICSGs. Many children and other family members are currently using computer technologies. Wuest (1993) also suggests that the research findings should be communicated with the participants and that discussion should include growth and directions for change in the political or social order.

Instead of using the telephone method of interviewing Hispanics, face-to-face interviews or focus groups would have been beneficial in exploring other reasons they are not yet inclined toward using ICSGs. This would be in congruence with the feminist stance. Cultural competence (Im et al., 2007) should be employed in the recruitment of Hispanics in research studies. For example, a Hispanic researcher should be linked with a Hispanic research participant in an effort to promote cultural competence. Also, as Brown et al. (2002) discovered, culturally appropriate recruitment techniques increased minorities' involvement in research. In addition, as Juarez et al. (1998) pointed out, patients should be approached by being nonjudgmental, sensitive, and above all, respectful of the individual. Lastly, Ashing-Giwa et al. (2002b) asserted that the health care system should be more culturally responsive to minorities by increasing staff diversity

and by being more knowledgeable about community resources and psychological service partnership or programs.

Very little research has been done with the Hispanic population regarding ICSGs. The need continues for more studies to investigate further what Hispanic attitudes are toward ICSGs.

Because there has been oppression of Hispanics and this group often feels powerless in terms of poverty and social status, Hispanics' lives might be enhanced by a researcher treating the participants with respect and placing value and significance on the exchanged communication (Fawcett & Buhle, 1995). Thus, future researchers should incorporate more feminist-perspective research studies for the Hispanic population and allow for more gender-sensitive studies. The goals would be to use culturally sensitive methods and flexibility and to design more research studies that would help give men and women a more equal voice in the research.

With a mean age of almost 44 years, participants in this study were not exposed to computers while they were growing up. Their children often have that advantage, at least to some degree in school. This familiarity with computers may in turn increase computer usage later in life, for example, in cancer support groups. In addition, demand for ICSGs may increase because, as the Hispanic population in the United States ages, they likely will follow the trend common among other population groups and develop an increased incidence of cancer (American Cancer Society, 2009).

Even though there is a paucity of information regarding Hispanic cancer patients' attitudes toward ICSGs, the existing knowledge should be used to provide direction for future research and for the development of cancer support groups that could meet the unique needs of Hispanic cancer patients. In terms of cost and given the challenges in today's health care system, there might be an added advantage of promoting online support groups as being more cost effective than using a car for transportation in order to get to a face-to-face support group, which itself might be more expensive to run than an online group.

CONCLUSION SUMMARY

A discussion of the findings was provided in this chapter. Findings for four themes that became apparent from the research were reviewed along with limitations of the study and conclusions. Finally, recommendations for nursing theory, practice, and research were made.

Appendix A: Sociodemographic Characteristics, Ethnic Identity, and Disease Status (English and Spanish)

Sociodemographic characteristics, ethnic identity, and disease status

1. When is your birth date?
   _____ So, I am _____ years old.
   Day/ month / year

2. What is your gender?
   _____ Female
   _____ Male

3. What is your highest grade or type of education you reached in school?

   _____ No school
   _____ Elementary school/ graduated
   _____ Middle school/ graduated
   _____ High school
   _____ Partial college
   _____ College (graduated)
   _____ Graduate degree

4. What is your religion?
   _____ Protestant
   _____ Catholic
   _____ Buddhism
   _____ Moslem
   _____ No religion
   _____ Others

5. Which one of the following best describes your marital status now?

	For how long?
_____ Married	_____ years
_____ Partnered, permanent relationship	_____ years
_____ Divorced/separated/no longer partnered	_____ years
_____ Widowed	_____ years
_____ Single, never partnered	_____ years

6. Are you currently employed outside of the home?
   _____ No
   _____ Yes
   If yes, what sort of work do you do?
   _____
   What are your main duties?
   _____
   How long have you worked at this job?
   _____ (month) or _____ (year)
   If less than 6 months working at this job, please describe the type of work you did before. _____
   How long did you work at that job?
   _____ (month) _____ (year)

7. Your annual family income is about _____ dollars, and is….
   _____ Totally insufficient for your family
   _____ Somewhat insufficient for your family
   _____ Sufficient for essential needs
   _____ More than sufficient

8. What is your ethnicity?
   _____ Hispanic
   _____ Non-Hispanic

9. You are:
   _____ Mexican
   _____ Puerto Rican
   _____ Central American
   _____ South American
   _____ Cuban
   _____ Dominican
   _____ Spanish
   _____ Other descent. Please specify your racial group _____.

10. Were you born in the United States?
    _____ Yes
    _____ No
    If the answer is 'no', please answer the following seven questions (10a -10g).

    10a. How long have you been in the United States?
    _____ months or _____ years

    10b. What is your food preference?
    _____ Exclusively American food
    _____ Mostly American food
    _____ About equally American and your own ethnic food
    _____ Exclusively your own ethnic food

    10c. What is your music preference?
    _____ Only American music
    _____ Mostly American
    _____ Equally American and your own ethnic music
    _____ Mostly your ethnic music
    _____ Only your own music

    10d. What do you prefer?
    _____ American customs only
    _____ Mostly American customs
    _____ Equally American and your own ethnic customs
    _____ Mostly your own ethnic customs

_____ Only your own ethnic customs

10e. Which of the following statements best describes your general ability to read and speak English?

_____ You read and speak English better than another language.
_____ You read and speak another language equally as well as English.
_____ You read and speak another language better than English.

10f. What is the ethnic origin of your close friends?

_____ All Americans
_____ Mostly Americans
_____ Americans and your own ethnic group equally
_____ Mostly your own ethnic group
_____ All your own ethnic groups

11. Please check one area indicating how you feel about your health.

_____ You are very unhealthy
_____ You tend to be unhealthy
_____ You don't know
_____ You tend to be healthy
_____ You are very healthy

12. Have you been diagnosed with cancer?

_____ No
_____ Yes

13. When did you get this diagnosis?

_____

14. What is the site of cancer?

_____

15. What is the type of cancer?

_____

16. What is the stage of cancer?

_____

17. What kinds of treatments have you received or currently receive related to cancer (please choose all that are applicable)?

_____ Radiation Therapy
_____ Chemotherapy
_____ Surgery
_____ Hormone therapy
_____ Others: please specify _____

Características sociodemográficas, la identidad étnica, y el estado de la enfermedad

1. Cuando es su fecha de nacimiento?
_____ Por lo tanto, tengo _____ años.
Día / mes / año

2. ¿Cuál es su sexo?
_____ Femenino
_____ Masculino

3. ¿Cuál es su más alto grado o tipo de educación que se había llegado en la escuela?

_____ Nada de esculela
_____ Escuela elemental educación
_____ Escuela media
_____ Secundaria
_____ parcial universidad
_____ Universidad (graduado)
_____ posgrado educacion

4. ¿Cuál es su religión?
_____ Protestante
_____ Católica
_____ Budismo
_____ Musulmana
_____ No religión
_____ Otros

5. Cuál de las siguientes opciones describe mejor su estado civil?

	¿Por cuánto tiempo?
_____ Casado	_____ años
_____ En conjunto, la relación permanente	_____ años
_____ Divorciado / separado / ya no se asoció	_____ años
_____ Viudo	_____ años
_____ Soltero, nunca se asoció	_____ años

6. ¿Está actualmente empleado fuera de la casa?
_____ No
_____ Sí
En caso afirmativo, ¿qué tipo de trabajo hace usted?
_____
¿Cuáles son sus principales funciones?
_____
¿Por cuánto tiempo ha trabajado en este trabajo?
_____ (Mes) o (año) _____
Si menos de 6 meses de trabajo en este trabajo, por favor describe el tipo de trabajo que hacía antes. _____
¿Cuánto tiempo has trabajado en ese trabajo?
_____ (Mes) (año) _____

7. Su ingreso familiar anual es de _____ dólares, y es….
_____ Totalmente insuficiente para su familia
_____ Algo insuficiente para su familia
_____ Suficientes para las necesidades esenciales
_____ Más que suficiente

8. ¿Cuál es su origen étnico?
_____ Hispano
_____ No-hispanos

9. Usted es:
_____ Mexicano
_____ De Puerto Rico
_____ De Centro América
_____ De América del Sur
_____ Cubano
_____ Dominicana
_____ Español
_____ Otros ascendencia. Por favor, especifique su grupo racial _____.

10. ¿Nació usted en los Estados Unidos?
_____ Sí
_____ No
Si la respuesta es 'no', por favor, responda a las siguientes siete preguntas (10a–10g).

10 a. ¿Cuánto tiempo hace que esta en los Estados Unidos?
_____ _____ Meses o años

10 b. ¿Cuál es su preferencia de los alimentos?
_____ Exclusiva comida de América
_____ La mayoría de comida de América
_____ Igualmente acerca de comida de América y su propia comida étnica
_____ Exclusivamente su propia comida étnica

10c. ¿Cuál es su preferencia musical?
_____ Sólo la música de América
_____ La mayoría musica de América
_____ Igualmente americano y su propia música étnica
_____ La mayoría de su música étnica
_____ Sólo su propia música

10d. ¿Qué prefiere?
_____ Costumbres de América sólo
_____ La mayoría de costumbres de América
_____ Igualmente costumbres de Americanos y de sus propios costumbres étnicas
_____ Mayormente su propio costumbres étnicas

_____ Sólo su propio costumbres étnicas

10e. ¿Cuál de las siguientes afirmaciones describe mejor sus generales capacidad de leer y hablar Inglés?

_____ Puede leer y hablar Inglés mejor que otra lengua.
_____ Puede leer y hablar otro idioma, así como igualmente Inglés.
_____ Puede leer y hablar otro idioma mejor que el Inglés.

10f. ¿Cuál es el origen étnico de sus amigos?

_____ Todos Americanos
_____ La mayoría son Americanos
_____ Americanos y de sus propios grupos étnicos por igual
_____ La mayoría de su propio grupo étnico
_____ Todos de sus propios grupos étnicos

11. Por favor, marque una zona que indica cómo se siente acerca de su salud.

_____ Usted es muy poco saludable
_____ Usted tiende a ser poco saludable
_____ No sabe
_____ Usted tiende a ser saludable
_____ Usted es muy saludable

12. ¿Le han diagnosticado cáncer?

_____ No
_____ Sí

13. ¿Cuándo obtenio este diagnóstico?

_____

14. ¿Cuál es el sitio del cáncer?

_____

15. ¿Cuál es el tipo de cáncer?

_____

16. ¿Cuál es la etapa del cáncer?

_____

17. ¿Qué tipos de tratamientos ha recibido o recibe actualmente relacionadas con el cáncer (por favor seleccione todas las que son aplicables)?

_____ Radioterápica
_____ La quimioterapia
_____ Cirugía
_____ La terapia hormonal
_____ Otros: por favor, especifique

_____

Appendix B: Study Information Form (English and Spanish)

Study Information Form

IRB APPROVED ON: (ORSC USE ONLY) *EXPIRES ON:*

Title: Hispanic cancer patients' attitudes toward Internet Cancer Support Groups (ICSGs)

IRB PROTOCOL #

Conducted By: Enrique Henry Guevara, MSN, RN, graduate nursing doctoral student

Of The University of Texas at Austin: *School of Nursing* Telephone: 512-632-6911

E-mail: hguevara@mail.utexas.edu

You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask any questions you might have before deciding whether or not to take part. Your participation is entirely voluntary. You can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time and your refusal will not impact current or future relationships with UT Austin or Shivers Cancer Center. To do so simply tell the researcher you wish to stop participation. The researcher will provide you with a copy of this consent for your records.

The purpose of this study is to evaluate the specific cultural viewpoints and factors of a small group of the Hispanic population in the area of attitudes towards Internet Cancer Support Groups and possible reasons for a lack of participation in Internet Cancer Support Groups.

If you agree to be in this study, we will ask you to do the following things:

- You will be asked to call the investigator by telephone for a discussion, verbally consent to agree to participate in the study.
- You will be asked survey and discussion questions by telephone.

Total estimated time to participate in study is sixty minutes

Risks of being in the study

- Participation in this study may be an inconvenience and some of the questions may make you uncomfortable or upset. Yet, you are free to decline to answer any questions you do not wish to answer or to stop participating in the project at any time.
- If the participant becomes fatigued, the researcher will stop the process and allow for a ten minute break in order to evaluate for the continuation of the process.

Benefits of being in the study: There are no benefits for participation in this study.

Compensation:

- Reimbursement for participation will be made by providing a Wal-mart gift certificate of ten dollars per participant. The reimbursement will be mailed out once you fulfill the requirements of this study.

Confidentiality and Privacy Protections:

- The data resulting from your participation may be made available to other researchers in the future for research purposes not detailed within this consent form. In these cases, the data will contain no identifying information that could associate you with it, or with your participation in any study.
- Telephone discussions will be audiotaped;
- Tapes will be coded so that no personally identifying information is visible on them;
- Tapes will be kept in a secure place (e.g., a locked file cabinet in the investigator's office);
- Tapes will be heard only for research purposes by the investigator and his or her associates;
- Tapes will be erased after they are transcribed or coded.

The records of this study will be stored securely and kept confidential. Authorized persons from The University of Texas at Austin, members of the Institutional Review Board, and (study sponsors, if any) have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a subject. Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

Contacts and Questions:

If you have any questions about the study please ask now. If you have questions later, want additional information, or wish to withdraw your participation call the researchers conducting the study. Their names, phone numbers, and e-mail addresses are at the top of this page. If you have questions about your rights as a research participant, complaints, concerns, or questions about the research please contact Jody Jensen, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects at (512) 232-2685 or the Office of Research Support and Compliance at

Study Information Form

IRB APPROVED ON: (ORSC USE ONLY) *EXPIRES ON:*

(512) 471-8871 or email: orsc@uts.cc.utexas.edu.

You will be given a copy of this information to keep for your records.

Forma de Información Para El Estudio

El título: Las actitudes de Hispanos' con cancer hacia Grupos de Apoyo de Cáncer de Internet
PROTOCOLO de IRB #
Realizado Por: Enrique Henry Guevara, MSN, RN, estudiante doctoral de enfermeria de La Universidad de Tejas en Austin: de Escuela de Enfermería: El teléfono 512-632-6911: Correro Electronico: hguevara@mail.utexas.edu

Le pedimos a Usted que tome parte en un estudio de investigación. Esta forma le proporciona con información sobre el estudio. El dirigente de esta investigación también le describirá este estudio a usted y contestará todas sus preguntas. Lea por favor la información debajo y pregunte lo que usted quizás tenga antes de decidir si ni no toma parte. Su participación es enteramente voluntaria. Usted puede negarse a participar sin pena o pérdida de beneficios a que usted de otro modo es permitido. Usted puede parar su participación en tiempo y su negativa no impresionará la corriente ni futuras relaciones con UT Austin ni de participar en otros sitios. Para hacer así le dice simplemente al investigador que usted desea parar la participación. El investigador le proporcionará con una copia de este consentimiento para sus registros.

El propósito de este estudio es de evaluar los factores culturales específicos de aspectos y fondo de un pequeño grupo de la población Hispana en el área de actitudes hacia grupos de apoyo y razones posibles para una falta de la participación en grupos de apoyo.

Si usted concuerda en estar en este estudio, nosotros le pidimos que usted haga las siguientes cosas:
• Le pedimos a Usted que llame a el investigador por teléfono para una discusión, verbalmente consentimiento a concordar en tomar parte en el estudio.
• Le vamos a preguntar las preguntas de la inspección y la discusión por teléfono.

Total estimó tiempo de tomar parte en el estudio sera sesenta minutos

Riesgos de estár en el estudio
• La participación en este estudio puede ser inconveniente y algunas de las preguntas le pueden hacer incómodo o disgustado. Todavía, usted es libre de

disminuir contestar cualquer pregunta que usted no desea contestar y parar tomando parte en el proyecto en cualquer tiempo.

Los beneficios de el estudio: No hay beneficios para la participación en este estudio.

La compensación:
• Reembolso para la participación será hecho proporcionando un vale-obsequio de diez dólares por participante. El reembolso será enviado al cumplir los requisitos de este estudio.

Las Protecciones de la confidencialidad y la Intimidad:
• Los datos que resultan de su participación pueden ser hechos disponible a otros investigadores en el futuro para propósitos de investigación no detallado dentro de esta forma del consentimiento. En estos casos, los datos no contendrán información de identificación que podría asociarse con usted, o con su participación en cualquier estudio.
• Las discusiones serán gravadas por cinta;
• Cintas serán codificadas para que no se identifica personalmente su información;
• Cintas serán mantenidas en un lugar seguro (por ejemplo, un archivador cerrado en la oficina del investigador);
• Cintas serán oídas sólo para propósitos de investigación por el investigador y sus socios;
• Cintas serán borradas después de que sean transcritos o son codificados.
Los registros de este estudio serán almacenados firmemente y serán mantenidos confidencial. Las personas autorizadas de La Universidad de Tejas en Austin, los miembros de la Tabla Institucional de la Revisión, y (patrocinadores de estudio, si cualquiera) tiene el derecho legal para revisar sus registros de investigación y proteger la confidencialidad de esos registros hasta el punto permitido por la ley. Todas publicaciones excluirán cualquier información que hará posible identificarle como un sujeto. A través del estudio, los investigadores le notificarán de nueva información que puede llegar a ser disponible y eso quizás afecte su decisión de quedarse en el estudio.

Contactos y Pregunta: Si usted tiene cualquier pregunta acerca del estudio pregunte por favor ahora. Si usted tiene mas preguntas más tarde, información adicional, o desea de retire su participación, llame los

investigadores que realizan el estudio. Sus nombres, los números de teléfono, y las direcciones de correo electrónico
están a la cabeza de esta página. Si usted tiene las preguntas acerca de sus derechos como un participante de investigación, las quejas, concierne, o pregunta acerca de la investigación por favor contacto Jody Jensen, Ph.D., la Silla, La Universidad de Tejas en Austin la Tabla Institucional de la Revisión para la Protección de Sujetos Humanos en (512) 232-2685 o la Oficina de Apoyo de Investigación y Conformidad en (512) 471-8871 o correo electrónico: orsc@uts.cc.utexas.edu.

Usted será dado una copia de esta información a mantener para sus registros.
Usted será ofrecido un resumen de las conclusiones del studio.

_____	_____
(Firma de participante)	(Fecha)
_____	_____
(Nombre impreso de participante)	(Fecha)
_____	_____
(Firma de Persona que Explica el Consentimiento)	(Fecha)
_____	_____
(Investigador)	(Fecha)

Appendix C: Brief Language-Based Acculturation Scale

NAME_____ ID# _____

BRIEF LANGUAGE-BASED ACCULTURATION SCALE
Richard A. Deyo, M.D.

1.)_____ **Muchos de nuestros pacientes hablan inglés y español, pero muchos hablan solo en inglés o español. Cual idioma prefiere hablar?**

1=inglés 2=español 3=otro 4=los dos, no tengo preferencia

_____ Some of our patients speak both English and Spanish, but many speak only one or the other. To improve our future contacts with you, we would like to know what language you prefer to speak.

1=English 2=Spanish 3=other:_____ 4=both, equally

2.)_____ **Cual idioma se habla más en su casa?**

1=inglés 2=español 3=otro 4=los dos, igualmente

_____ What language is most often spoken in your home?

1=English 2=Spanish 3=other 4=both, equally

3.)_____ **Cual idioma habló primero (de niño)? 1=inglés 2=español 3=otro**

_____ What was your first language as a child? 1=English 2=Spanish 3=other

4.)_____ **Muchos de nuestros pacientes no pueden leér bien inglés o español. Puede leér inglés?**

1=sí, todo 2=sí, un poco 3=muy poco 4=nada

_____ Many of our patients have difficulty reading in either English or Spanish. Do you read any English?

1=yes, anything 2=some 3=very little 4=none

Scoring:
- Question #1: 1 point for English; 0 points for Spanish or both
- Question #2: 1 point for English or both; 0 points for Spanish
- Question #3: 1 point for English; 0 points for Spanish or other
- Question #4: 1 point for 1, 2, or 3; 0 points for answer #4

Summary score = sum of points for the 4 items

Source: Deyo, R., Diehl, A., Hazuda, H., & Stern, M. (1985). A simple language-based acculturation scale for Mexican Americans: Validation and Application to Health Care Research. *American Journal of Public Health*, 75, 1, 51-55.

Interviewer # _____
Date _____

Appendix D: Interview Questions

The questions are:

1. When you have questions about your medicine or your disease, who do you talk to? For example, do you ask your spouse, children, boss, priest, or friends? Who else do you ask? Why or why not?
2. Explain any type of support that you receive from other sources, such as your family, church, other support groups, etc.
3. What things help you to decide to be in a support group? Is it more comfortable to be in a group of women or men only? Why or why not?
4. How would you feel about trusting others in the support group with details about your disease?
5. What are your feelings about others treating you with respect and dignity during a support group and do you feel that the support group would benefit you?
6. Who would you need permission from in order to attend a support group or an Internet support group? Describe the type of transportation that would be available to you in order to get to a support group.
7. Do you have a personal computer and have you ever used a personal computer?
8. Sometimes people that have the same disease communicate by using the computer to help and support one another. One example of this is an Internet cancer support group. If you had access to a computer and if someone showed you how to use the computer, would you be interested in communicating with other people by using a computer? Why or why not?
9. If you had access to a computer, would you have a preference for the information to be in English or Spanish? Why or why not?

10. If you had a computer, would you be interested in learning more about your disease by information on the Internet about your disease? Why or why not?
11. Anything else that you would like to add about your feelings towards Internet cancer support groups?

Preguntas

Las preguntas son:

1. Cuando usted tiene preguntas acerca de su medicina o su enfermedad, con quien habla usted? Por ejemplo, ¿le pregunta a su cónyuge, hijos, jefe, sacerdote, o amigos? ¿Quién más le pregunta? ¿Por qué o por qué no?

2. Explique cualquier tipo de apoyo que recibe de otras fuentes, tales como su familia, la iglesia, o otros grupos de apoyo.

3. ¿Qué cosas le ayuda a decidir estar en un grupo de apoyo? ¿Es más cómodo estar en un grupo de las mujeres o los hombres? ¿Por qué o por qué no?

4. ¿Cómo se siente acerca de dar la confianza a otros en el grupo de apoyo con los detalles acerca de su enfermedad?

5. ¿Cuáles son sus sentimientos sobre el tratamiento de los demás que lo traten con respeto y dignidad en un grupo de apoyo y cree usted que el grupo de apoyo le beneficiaría a usted?

6. ¿A quién necesita preguntar por permiso par ir a un grupo de apoyo o un grupo de apoyo de Internet? Describe el tipo de transporte que esta a su disposición con el fin de llegar a un grupo de apoyo.

7. ¿Usted tiene una computadora? Nunca ha usado una computadora ?

8. A veces, las personas que tienen la misma enfermedad se comunican tocante el uso de la computadora para ayudar y apoyar a una de la otra. Un ejemplo de esto es un grupo de apoyo de cáncer de Internet. Si usted tiene acceso a una computadora y si a alguien le ensena cómo usar la computadora, usted estaría interesado en la comunicación con otras personas tocante el uso de una computadora? ¿Por qué o por qué no?

9. Si usted tiene acceso a una computadora, usted tiene preferencia por la información que sea en Inglés o Español? ¿Por qué o por qué no?

10. Si usted tenia una computadora, está usted interesado en aprender más acerca de su enfermedad por la información en la Internet acerca de su enfermedad? ¿Por qué o por qué no?

11. Alguna otra cosa que quisiera agregar sobre sus sentimientos hacia grupos de apoyo de cancer por el Internet?

Appendix E: Institutional Review Board Approval

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 (512) 471-8871 - FAX (512 471-8873)
North Office Building A, Suite 5.200 (Mail code A3200)

FWA # 00002030

Date: **07/15/08**

PI(s): **Henry Guevara** Department & Mail Code: **NURSING SCHOOL** **D0100**

Dear: **Henry Guevara**
IRB APPROVAL – IRB Protocol # **2008-04-0086**

Title: **2008-04-0086 Hispanic Cancer Patients' Attitudes Toward Internet Cancer Support Groups (ICSGs)**

In accordance with Federal Regulations for review of research protocols, the Institutional Review Board has reviewed the above referenced protocol and found that it met approval under an Expedited category for the following period of time: **07/15/2008 - 07/13/2009**

Expedited category of approval:
___(**1**) Clinical studies of drugs and medical devices only when condition (a) or (b) is met. (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review). (b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

___(**2**) Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows: (a) from healthy, non-pregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or (b) from other adults and children2, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

___(**3**) Prospective collection of biological specimens for research purposes by Non-invasive means.
Examples:

(a) hair and nail clippings in a non-disfiguring manner;
(b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction;
(c) permanent teeth if routine patient care indicates a need for extraction;
(d) excreta and external secretions (including sweat);
(e) uncannulated saliva collected either in an un-stimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue;
(f) placenta removed at delivery;
(g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor;
(h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the Process is accomplished in accordance with accepted prophylactic techniques;
(i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings;
(j) sputum collected after saline mist nebulization.

☐ **(4)** Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications). Examples:

(a) physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
(b) weighing or testing sensory acuity;
(c) magnetic resonance imaging;
(d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography;
(e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

___ **(5)** Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt).

___ **(6)** Collection of data from voice, video, digital, or image recordings made for research purposes.

_X_ **(7)** Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt).

____ Please use the attached approved informed consent

__X__You have been granted Waiver of Documentation of Consent
According to 45 CFR 46.117, an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either:

___ The research presents no more than minimal risk
AND
___ The research involves procedures that do not require written consent when performed outside of a research setting
<OR>
_X_ The principal risks are those associated with a breach of confidentiality concerning the subject's participation in the research **AND**
_X_ The consent document is the only record linking the subject with the research
AND
_X_ This study is not FDA regulated (45 CFR 46.117)
AND
_X_ Each participant will be asked whether the participant wishes documentation linking the participant with the research, and the participants wishes will govern.

____ You have been granted Waiver of Informed Consent
According to 45 CFR 46.116(d), an IRB may waive or alter some or all of the requirements for Informed consent if:

___ The research presents no more than minimal risk to subjects;
___ The waiver will not adversely affect the rights and welfare of subjects;
___ The research could not practicably be carried out without the waiver; and
___ Whenever appropriate, the subjects will be provided with additional pertinent information they have participated in the study.

___ This study is not FDA regulated (45 CFR 46.117)

RESPONSIBILITIES OF PRINCIPAL INVESTIGATOR FOR ONGOING PROTOCOLS:

(1) Report **immediately** to the IRB any unanticipated problems.

(2) Proposed changes in approved research during the period for which IRB approval cannot be initiated without IRB review and approval, except when necessary to eliminate apparent immediate hazards to the participant. Changes in approved research initiated without IRB review and approval initiated to eliminate apparent immediate hazards to the participant must be promptly reported to the IRB, and reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the participants continued welfare.

(3) Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to take part.

(4) Insure that only persons formally approved by the IRB enroll subjects.

(5) Use **only** a currently approved consent form (remember approval periods are for 12 months or less).

(6) **Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of participants and information.**

(7) Submit for review and approval by the IRB all modifications to the protocol or consent form(s) prior to the implementation of the change.

(8) Submit a **Continuing Review Report** for continuing review by the IRB. Federal regulations require **IRB review of on-going projects no less than once a year** (a Continuing Review Report form and a reminder letter will be sent to you 2 months before your expiration date). Please note however, that if you do not receive a reminder from this office about your upcoming continuing review, it is the primary responsibility of the PI not to exceed the expiration date in collection of any information. Finally, it is the responsibility of the PI to submit the Continuing Review Report before the expiration period.

(9) Notify the IRB when the study has been completed and complete the Final Report Form.

(10) Please help us help you by including the above protocol number on all future correspondence relating to this protocol.

Thank you for your help in this matter.

Sincerely,

Jody Jensen, Ph.D., IRB Chair

Protocol # Approval dates: - 2008-04-0086 07/15/2008 07/13/2009

Appendix F: Approval from Brackenridge Hospital

RESEARCH STUDY AGREEMENT

Daughters of Charity Health Services of Austin d/b/a Shivers Cancer Center ("SETON") a Texas not-for-profit corporation, and Enrique Henry Guevara ("Researcher") have entered into this Agreement effective as of the date this Agreement is signed by the both parties below, to establish a relationship with regard to a research study to be conducted in part at a SETON facility, and to protect confidential and proprietary information obtained by Researcher from SETON. The parties hereby agree to abide by the following terms and conditions:

1. SETON acknowledges that Researcher has received approval from SETON's Clinical Research Steering Committee to conduct a research project entitled "Hispanic Cancer Patients' Attitudes Toward Internet Cancer Support Groups" (the "Study"), in conjunction with University of Texas at Austin, in part at a SETON facility.

2. Researcher shall be responsible for all aspects of the Study, including but not limited to:

   a. Identifying prospective Study subjects;
   b. Approaching potential Study subjects to inquire about their willingness to participate in the Study;
   c. Obtaining the informed consent of each Study participant prior to enrolling the participant in the Study;
   d. Administering all study questionnaires and gathering all Study-related data;
   e. Conducting all follow-up contacts with Study participants; and
   f. Conducting all Study-related data analysis.

3. In connection with the Study, SETON may disclose to Researcher or Researcher may learn or have access to confidential or proprietary information; SETON policies and procedures; and standards and practices of SETON staff and/or Medical Staff regarding the care and treatment of patients (collectively, "Confidential Information"). Such Confidential Information is provided by SETON to Researcher solely and exclusively for the purpose of the Study. all Confidential Information disclosed to or learned by Researcher by SETON shall be treated by Researcher as confidential or proprietary information of SETON or patients of SETON.

   a. Researcher shall protect Confidential Information with the highest degree of care. Researcher shall not provide or disclose Confidential Information obtained by Researcher from SETON to anyone, other than with advance written authorization from SETON. Researcher shall take all actions necessary to maintain and preserve the Confidential Information disclosed or learned by him, including, without limitation, (a) affixing to all documents and data (in whatever form or medium) a notice or label which indicates the proprietary and confidential nature of the materials contained therein, (b) informing him faculty advisor and any other individuals with access to the Confidential Information of its confidential and proprietary nature, and (c) securing all Confidential Information in him possession in a manner which will not permit access by other persons.

   b. Researcher will not use or reproduce Confidential Information obtained by him from SETON for any purpose other than in connection with the Study. Upon completion of the Study, or earlier if requested by SETON, Researcher will return to SETON, or, at SETON's option, destroy all materials embodying Confidential Information of SETON, as well as any copies, or other reproductions of such information.

   c. The obligations of Researcher under this Agreement shall not apply to any information which: (a) is rightfully received from a third party by Researcher without disclosure restrictions; (b) becomes publicly available through no wrongful act or omission of Researcher; or (c) is approved in advance for release in writing by SETON.

4. While conducting the Study on SETON premises, Researcher agrees to abide by all applicable federal, state and local laws, regulations and ordinances; SETON policies, procedures, rules and regulations; and the "Ethical and

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Religious Directives for Catholic Health Care Services." Researcher further agrees to cooperate with reasonable instructions from SETON's staff the while conducting the Study. If during the course of the Study, Researcher will be performing any hands-on patient care or any other activity which would require Researcher to be credentialed as a staff member of the SETON medical or allied professional staff, Researcher represents and warrants that Researcher has been so credentialed and will remain appropriately credentialed during the entire term of the Study.

5. Researcher shall hold harmless, indemnify, and defend SETON from and against any and all claims, demands, actions, losses, costs, damages and expenses, including reasonable attorneys' fees, arising from or out of any negligent or willful acts or omissions of Researcher, his agents or representatives in connection with the performance of the Study. This obligation shall survive the termination of this Agreement for any reason.

6. In connection with the performance of the Study, Researcher shall be at all times and is acting and performing as an independent contractor, and shall not be considered to be an employee, servant, partner, joint venturer, agent, or personnel of Seton.

7. Upon completion of the Study, Researcher shall deliver to SETON a copy of any written report, including data compilation and analysis, produced in connection with the Study. The written report produced in connection with the Study shall not contain any patient identifying information.

8. Researcher shall not assign or transfer his rights, duties, or obligations under this Agreement without the prior written consent of the duly authorized representative of SETON.

9. This Agreement shall be governed, construed and interpreted in accordance with the laws of the State of Texas.

10. This Agreement represents the sole and complete agreement of the parties with regard to the subject matter hereto. The Agreement may be modified or amended only by the written agreement of both parties.

11. This Agreement shall terminate automatically upon the completion of the Study. This Agreement may also be terminated by SETON immediately upon its reasonable determination that continuation of the Study at SETON will be detrimental to SETON's interests or the interests of SETON's patients. Either party may terminate this Agreement without cause upon 30 days prior written notice to the other. However, notwithstanding any termination of this Agreement, the obligations of Researcher to maintain the confidentiality of the Confidential Information shall survive such termination.

This Agreement is executed by the parties, effective as of the later date set forth below.

RESEARCHER

Enrique Henry Guevara Date: 9-12-08

Enrique Henry Guevara

Address: 6807 Lakewood Forest Drive
George town, TX 78633

DAUGHTERS OF CHARITY HEALTH SERVICES OF AUSTIN
D/B/A SHIVERS CANCER CENTER

By: Thomas E. Gallagher Date: 10/4/08

~~James O. Lindsey, M.D.~~ Thomas E. Gallagher
~~Sr. Vice President - Medical Affairs~~
Sr. VP - Business Development

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Vita

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